The 'Work' of Visually Impaired People:
Emplotting the Self in Order to Transform Others

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Declaration

I, Annamaria Dall'Anese, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

This thesis outlines how blind and partially sighted people in an English metropolis therapeutically emplot, i.e. narratively reframe their lives in the face of sight loss, whether adventitious or congenital. It shows how such emplotment, which often leads them to incorporate their disability into their lives, requires multiple forms of narrative 'work': joining the visually impaired community, finding a new meaning in one's life and, importantly, in one's professional life are all consuming but ultimately rewarding activities in the transformational journeys of people with sight loss.

I argue that my participants' therapeutic emplotment, which is always precarious, is strengthened by the fact that it can function as a model for other people's emplotment and that it is co-constructed. By demonstrating what they have achieved in their lives in spite of, or even thanks to, their sensory loss, visually impaired people can spread to others the same wish for self-improvement. Crucially, seeing the positive repercussions their spoken or unspoken narratives have on others reinforces the newly recrafted personal stories by which they orient their lives.

This thesis offers an alternative voice to the medical anthropology literature that couples disability with reduced employability and distress. It also develops the concept of therapeutic emplotment by suggesting that it can be co-constructed and that it can have an influence on other people's narrativization of their own lives.

Impact Statement

As the first broad ethnographic study of visual impairment in England, this thesis offers precious insights to policy makers, both those in this country and those elsewhere. Firstly and more broadly, it presents a textured ethnographic account of the physical and societal barriers that blind and partially sighted people still face when trying to be active members of society in a busy metropolis. This research gives a more humanistic perspective on the issues documented elsewhere by reports, surveys and statistics, such as isolation and impaired mobility.

Secondly and more specifically, the thesis has the potential to inform occupational programmes aimed at people with disabilities. At present, Government policies promote the integration of disabled people into mainstream employment. This thesis argues for a more diverse choice of professional opportunities for people with disabilities. For instance, it advocates supported workplaces as an additional, valuable option for members of society who do not consider themselves suitable for competing in the open job market.

Thirdly, this thesis gives clinicians, and in particular ophthalmologists, the opportunity to look beyond the pathology and to regard their patients as socially situated individuals. Thanks to an ethnographic account of a great variety of people with sight loss, medical professionals can learn what the lives of those they care for are like outside of the clinic. Moreover, the anthropological and non-anthropological literature cited allows them to learn more about the historical background and the social science debates on sight loss, as well as disability in general.

Finally, by presenting the voices of a diverse selection of blind and partially sighted people, the thesis invites policy makers to (continue to) take their perspectives into account when designing programmes that affect their daily lives and wellbeing. It also encourages decision-makers to appreciate the benefits that the knowledge gained from studies of disability can have on society at large. Practical solutions that emerge from people with sight loss can have positive effects when transferred to other populations. Implementing a conceptual shift whereby diversity informs the mainstream can help fight against the exclusion of and the discrimination against many individuals who, in spite of a prevailing discourse on equality, are isolated in and by our society.

I certainly would never have chosen blindness
but the extraordinary paradox is
that going blind has taught me to see more and differently

Sargy Mann, painter (2016:28)

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Acknowledgements

Chapter 1. Introduction: Visual Impairment, Narrative, and Work

1.1 Rationale behind the Project, Methodology and Ethics

My interest in visual impairment was sparked by my passion for the visual arts. As a trained photographer and a lover of museum and galleries, I was intrigued by the keenness of some people with sight loss to come to appreciate a work of art through audio description. How could words,[1] something that I equally cherish, stand in for colour and light, and for the upset geometries of Georges Braque? As a way of finding my own 'arbitrary location' (Candea 2007), I began by approaching people with sight loss who frequented various cultural organisations in town, as well as other individuals with whom they put me in touch. This is how my first subset of participants, those recruited on an individual basis, was formed. The activities I took part in alongside them and the conversations I had with them spanned most of the facets of their daily lives, from transport to religion, from discrimination to cooking. It became apparent that, just as there were individual differences, common challenges were faced by visually impaired people. A significant one was the struggle to retain or secure employment; another one was the extra time and effort put into a wide range of daily activities. The topic of work therefore asserted itself as in need of research on two levels: the narrow and professional, and the broad and quotidian.

As my network of acquaintances, and friends, among visually impaired people thickened, I felt the need to narrate their singularities and describe their commonalities. From the first prong of this issue originated the 'portraits,'[2] which I wrote on informants from all of my three participant groups. I felt that only by recounting the bundle of concerns that a particular participant experienced while situated in their own life course, in their own familial and social context could I give justice to the importance, or the gravity, of those concerns. The portraits may omit or alter biographical details for the purpose of confidentiality, but they are not composite

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[1] To counter my own scepticism on the power of words, notice that 19th century Laura Bridgman, the first deaf and blind person to learn language, defined her capacity to think through words as her 'fourth sense' (Freeberg 1994:315, Freeberg 2001:80-81).

[2] In using this term, I follow a person-centred, interpretative anthropological tradition (see Crapanzano 1980).

or fictive characters: they are real stories of real people, which I collected over many informal encounters and multiple interviews. On the other hand, the common traits of the people I recruited on a one-to-one basis began to emerge not only as topics for research, but also as concrete links between individuals that I had met on separate occasions. Conversations revealed previously unknown common acquaintances, sight loss websites showed faces I had seen in a different context, different people turned out to be the users of the same charitable organisation. The atomised series of individuals with whom I had started my research started taking the shape of a community. Nevertheless, I was aware that this approach may lead me to consider only participants who had already come to terms with their sight loss. I ran the risk of excluding potential informants who may be well-positioned to comment on one of the most socially severe consequences of visual impairment: solitude. It is one of the limitations of this thesis not to be based on interactions with completely isolated individuals, who, by definition, were difficult to identify and reach. However, I tried to counter this by volunteering at a sight loss charity, which I call Sunshine, catering in particular for people in the process of adapting to their condition. Sunshine also allowed me to gain first-hand experience of one of the numerous non-profit institutions helping people with sight loss that are present in the city. Its users are my second group of participants.

Finally, as I was searching for opportunities to delve deeper into what employment meant for visually impaired people, I came across Spring. The name of the organisation, as well as the type of product, has been changed and other information may have been changed or omitted in order to comply with the non-disclosure agreement I was asked to sign by the company. As the only remaining organisation in town established to employ people with sight loss, it was an obvious choice as my third research site. While this thesis does not feature an ethnography of either Spring or Sunshine as organisations, it does present an ethnography of the shop floor at Spring (chapter 3).

My three research groups included people self-identifying as (i.e. not necessarily registered as) either blind or partially sighted, with either adventitious or congenital

sight loss.[3] In spite of this diversity, I was struck by the fact that all of my participants shared with me personal narratives in which sight loss was an important, but not detrimental component. These narratives had been hard-won. Indeed, the most draining type of 'work' that visually impaired people have to do is, I argue, the narrative 'work' of reframing their lives in the face of sight loss. I use 'work' between inverted commas to refer to non-professional activities, whereas I use work without inverted commas to refer to either professional work, paid or unpaid, or to the first and the second type of work combined. All of my participants provided ample evidence of 'work': besides the narrative work, which is central to this thesis, there was the extra effort they had to put in specifically because they were visually impaired, such as white-cane training, or because doing something as simple as ordering a meal may require additional struggle.

I hasten to add, however, that in spite of my emphasis on work my fieldwork was overall a joyful enterprise: my participants sometimes shared their tiredness and dejection, but the atmosphere that pervaded our time together was more often characterised by friendliness, and, whenever I helped them with something, no matter how little, gratitude. 'Work' occasionally emerged in the recollection of how dreadful that journey had been, how long that wait, or how nerve-racking that conversation, only to disappear back into the background, like a leading actor of few words. Similarly, my participants' use of their experiences to change the public's perception of disability was subtle, and relied more on their active involvement in various activities (professional, philanthropic, recreational, mundane) than on overt persuasion. Rather than mastery, it was craft (Sennett 2004[2003]:83–99, see chapter 7). The result of their activities was palpable in the attitude of friends, colleagues, volunteers, and all other people who had known them long enough to treat them with empathy rather than sympathy, to appreciate their capabilities but not to regard them with wonder.

Methodologically, in order to elicit the stories that eventually became both the source of the portraits and the foundational material of the rest of the thesis, I found it helpful to ask very open-ended questions. In particular at the beginning of my research, I

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[3] For an explanation of the ophthalmological terms, see 'Visual Impairment: The Disease' below.

liked to give my participants the freedom to talk about their lives or the issues that mattered the most to them. My research topics, narrative and work, in its dual nature of professional and non-professional 'work,' can be regarded as research findings of a project that started as an ethnography with a very broad scope. What I found useful in order to retain my participants' narratives from a methodological perspective was to audio-record our interviews, and sometimes our conversations during other moments of fieldwork, for instance when we visited places that had a connection to their personal history. What my audio-recorder captured were the words of research participants attempting to be informative, but their stories, sometimes in their entirety, sometimes just in part, also felt like the fruit of a long period of elaboration. From William's exquisitely crafted life narrative to the worker recounting to me that she had started in her present job on 'March 1st' of a given year, narrative was not something they had produced for an anthropologist, but part and parcel of whom they had become.

I believe my task, and one of the purposes of this thesis, is to weave the stories I was entrusted with into a narrative that highlights their recurring themes and does not eschew their contradictions. The argument that runs through my thesis is the narrative transformation of the self that sight loss entails, and the culmination of the thesis is the transformation that such emplotted, i.e. narrated self may give rise to in others. When, in spite of all challenges, a visually impaired person first steps outside of their home, they also take a step towards making society more aware of the diversity of life experiences. They therefore have the potential to set in motion a change that is social as well as personal. If, metaphorically speaking, my interlocutors throw a stone of transformation into a pond, my thesis reaches the reader as the last ripple aspiring to enact that transformation.

I am much indebted to Spring and its employees, Sunshine and its users, and all of my individually recruited participants for taking part in my research. The names of all organisations and informants have been changed, and demographic, biographical and other details may have been changed or omitted with the aim of making both individual informants and organisations as unrecognizable as possible. Interview transcripts have been edited slightly so as to improve legibility while preserving the talking style of the interviewee. I obtained informed consent from all participants with

whom I conducted interviews or participant observation. I did so by using the information sheet for participants and the informed consent form approved by the Department of Anthropology. My fieldwork was also informed by my interactions with other sight loss organisations, for instance as a volunteer, and by conversations with sighted people involved with sight loss in a professional or voluntary capacity. Whenever actual data was used for the present research, I obtained informed consent from the relevant individuals. Although I learnt Braille Grade 1 (uncontracted), it never became necessary to use it to communicate the intent of my research to my participants, who opted either for signing a paper form or for giving their consent on an audio-recorder.

As a sighted researcher, I am fully aware that my knowledge of visual impairment is merely intellectual. I wore a blindfold to walk in a quiet neighbourhood with the help of a white cane and a blind friend[4] and, although the experience was informative, I soon abandoned the hope that it would give me a full understanding of the complexities of sight loss. Even after conducting two years of ethnographic fieldwork (part-time) with over 40 visually impaired participants in different settings, I am aware of my incapacity to fully comprehend the effects of sight loss on a person's life. One of the aims of the thesis is to highlight the variety of life experiences in the face of disability. On this basis, it could be argued that my lack of knowledge of the consequences of visual impairment is an ontological problem rather than an epistemological one: such consequences would be peculiar to my life, and would need to be learnt experientially rather than from other people.

Given my position as a sighted researcher, I was anticipating that some of the people I approached to participate in my research would meet me with a 'nothing about us without us' (Charlton 1998) attitude.[5] On the contrary, I found willingness or even eagerness to help. This may be due to the fact that, as an ethnographer, I was by definition going to interact with them in the long term, as opposed to interviewing them briefly as a journalist or observing them detachedly as a natural scientist. Yet, I am aware that many anthropology colleagues encounter barriers when entering the

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[4] See Deshen who, for the same reasons, never actually wore a blindfold (1992:9); cfr Hammer, who said that she never pretended to 'go-blind' or to purport to know how blindness felt (2013).
[5] See Ronald Berger's experience in Berger 2004:798-799.

field. These are often caused by the suspicion informants have regarding what the anthropologist, after leaving the field, may publish about them. I am therefore especially grateful to my participants for the trust they put in my project and in myself as a person. I am thankful to them all the more so since, thanks to my doctoral project, I have come to realise the struggles that all individuals who, for different reasons, diverge from the mainstream have to face. I have also come to appreciate the complexity of the different factors that, stigmatising or not, make us unique.

I should point out that, although I have endeavoured to represent my contributors' views faithfully, this thesis is the fruit of my own reflections on our interactions. Therefore, the arguments that I put forward and the opinions that I express in this work are entirely my own. Moreover, although my participants came from a diversity of socio-economic, educational and ethnic backgrounds and had different sight conditions, this work is a small-scale qualitative study written in a humanistic vein. Its purpose is to offer a 'thick description' (Geertz 1973) of the lives of my participants and to use anthropological theory to elaborate the significance of their narratives. Its ultimate aim is to offer the reader a new perspective not only on people with sight loss, but also on those who, because of other factors, may be seen as leading undesirably different lives.

The setting of this study is a busy metropolis in England, which I call Donchester. By changing the name of the city, I aim to provide an additional layer of confidentiality to my informants. Donchester more than simply framed the lives of my participants: it hindered them with crowds, enriched them with opportunities and facilitated it logistically with its transport network. It stressed them with bureaucracy and annihilated them with indifference, but also inspired them with humanness and delighted them with friendliness. Donchester will come into view at different points of my thesis, and so will Englishness, which inevitably permeates the study. As will be explained in chapter 2, one of its manifestations was independence, a value that my participants shared with the rest of society.

1.2 Structure of the Thesis

Visual impairment, whether congenital or adventitious, poses challenges on a personal and on a professional level, which may have repercussions on a person's sense of self. Nevertheless, people create personal narratives that lay emphasis on the positive role of sight loss in their lives, including their professional lives. The process of 'narrativization' or 'emplotment,' which are terms I use interchangeably, manifests itself in different ways. This thesis presents different types of narrative 'work' in a *crescendo*: from the hesitant attempt to reframe one's life as 'visually impaired' by joining the visually impaired community, to the confident desire to stir others by sharing one's personal story of overcome difficulties.

In this introductory chapter I clarify the terminology related to visual impairment, as well as the meaning of concepts that will be central to the thesis: visual impairment, narrative, and work. I conclude the chapter with the portrait of Dietlinde: her story, which describes her need to adjust her personal, social and professional lives to sight loss, gives substance to the three cardinal themes of the present research.

Chapter 2 is centred on the visually impaired community, or VI (*vee-eye*) community, as it is sometimes called for short. In spite of the diversity of life situations among visually impaired people, there is such a thing as a visually impaired community in Donchester. I argue that the negotiation of whether and to what degree to belong to this community requires a lot of 'work' and acts as a proxy for belonging to the broader category of 'visually impaired person.' Such negotiation is often the first type of narrative 'work' that visually impaired people perform in order to come to terms with their disability, regardless of whether this is congenital or acquired. I also contend that the emotional work of becoming part of the visually impaired community can be therapeutic. In fact, the performance of a plethora of mundane activities aimed at getting by in one's daily life is a type of 'work' that unites different visually impaired people into a community of mutual understanding. Overall, this chapter highlights the tension between the desire for independence expressed by people with sight loss and the benefits they derive from being part of the visually impaired

community. I illustrate this primarily with data from Sunshine and with the portrait of its user Sam. This chapter also presents the social model of disability as an important emic framework and calls attention to the socio-economic factors that impinge upon visually impaired people.

The third chapter is an ethnography of the shop floor at Spring, which is the only institution specifically created to employ people with sight loss that survives in Donchester. This is a parenthetical chapter in which I divert my focus from narrative to the peculiarities of this workplace in order to lay the foundations for chapter 4. In particular, I explain the factors because of which workers are employed at Spring or, as they say, 'inside,' rather than in mainstream employment, i.e. 'outside': the temporal framework offered by a job at the factory, the workers' educational background and social class, financial circumstances, and the sociality of the shop floor. At the end of the chapter I focus on the career of a particular worker, Jim, who is now retired. His narrative conveys both resilience in the face of adversity and competence: by working at a variety of different companies and by pursuing continuous training he forged a professional and personal self that defies the picture of passivity and unemployment that has historically been associated with sight loss.

In chapter 4 I delve deeper into what 'meaningful employment' means for workers at Spring, who have developed their own 'narratives of competence' and 'overcoming narratives' (Bloom 2019:123)[6] in order to reframe their lives in the face of sight loss, and also to alter people's perception of disability. By describing the pivotal role that work proper plays in their narratives, I also point out the culturally embedded nature of therapeutic emplotment: in spite of the fact that Spring is in some ways a secluded environment, workers are receptive to the broader cultural narrative on the importance of not being out of work. However, emplotment is not always beneficial: while workers appreciate the benefits of a job at Spring, they see it as the only place where they can be employed, which prevents them from imagining alternative professional futures.

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[6] Cfr Berger 2004 and 2008 on the debate on whether the phenomenon of 'supercrip' athletes helps or hinders the cause of disabled people.

Chapter 5 foregrounds the narrative 'work' that my individually recruited participants had to carry out in order to envisage themselves in a life with less sight or none. I delve deeper into the notion of therapeutic emplotment and observe that it may conform to particular patterns, namely that of the quest narrative (Frank 1995:115–136). I argue that newly recrafted life narratives are fragile and need to be constantly sustained. I show that a plethora of 'work' activities may be deployed in this respect, but also that a strictly professional transformation can be pivotal to therapeutic emplotment, in particular if it entails sharing one's positive life narrative with others. Quite appositely, the chapter concludes with the portrait of William, who became a professional storyteller following sudden sight loss.

In chapter 6 I argue that a certain continuity between old and new self is instrumental in creating a stable life narrative. I also reflect on the importance that sharing one's emplotted life has for all of my informants. In Richard Sennett's definition, they are craftsmen rather than masters (2004[2003]:83–89): they share what they have become with the intent not to be emulated, but to inspire their interlocutors to creatively recraft their own lives. I argue that therapeutic emplotment may influence others and lead them to reframe their lives in a positive way, too. Therapeutic emplotment is a model in the sense meant by Sennett: it is the product of something done not in order to impress others, but in order to provide them with something to work on themselves (Sennett 2006:101 – 103). It is excellent and it inspires others not to imitate its excellence, but to draw upon it in order to create something innovative and original (ibid.). I also contend that therapeutic emplotment is co-constructed: those who emplot their lives and share them with others realise the positive effects that their own stories have on their interlocutors. This, in turn, makes them feel the meaningfulness of their newly recrafted life for others, which can make their therapeutically emplotted self less vulnerable to setbacks. This chapter also invites the reader to be inspired by the meaningfulness of these newly recrafted lives just as Yussef's audiences are inspired by his talks. Visually impaired from birth and now totally blind, he has found in both engineering and public speaking a way to convey what he has become, personally and professionally, thanks to his life challenges, including sight loss.

In the concluding chapter I advocate treasuring our common humanity in order to problematise the sighted/sightless divide. I also look back at my participants' collaboration on my doctoral project to observe that, just as this thesis has been an opportunity for me to see what lies behind the bleak image of sight loss, so has it been an opportunity for my informants to feel the benefits of sharing their life experiences with a wider audience.

Thanks to the discussion presented in the final chapter, the portraits that punctuate the thesis ultimately acquire a function that is more than illustrative (cfr. Crapanzano 1980). Like the joint creation of a sitter and a painter (Bray 2015), they are the fruit of a collaboration and embody the co-construction of therapeutic emplotment that is at the heart of the thesis. Like portraits in a gallery, the heterogeneity of their styles belies the similarity of their intent: conjuring the singularity of the life of a participant through the serendipity of an ethnographic encounter. Although, or perhaps because of the fact that I approached each of my informants with questions that were equally open-ended, each of them steered the encounter in their preferred direction. As their interlocutor, I was given not only different topics to explore, but also different roles to play. Co-worker, guide, fellow art lover, researcher… These roles, as well as the activities my participants and I took part in, framed the portraits, and are described at the beginning of each of them in order to contextualise them.

Among the informants who took part in this project, including those featured in the portraits, some had congenital, some adventitious sight loss. In a thesis centred on narrative, it may seem unwarranted to bring together the experiences of people who lost their sight in adulthood, if not in old age, and those who did not even have any memories of sight. After all, the experience of having been sighted has a bearing on if and to what degree one perceives oneself as different in a society that consists mainly of fully sighted people. It may also influence the perception that people have of their own disability and capability. My participants pointed out that, in order to understand the life experiences of visually impaired people, it was important to consider whether their sight loss was congenital or adventitious. However, it was one of the findings of my research that this difference, albeit significant, had to be considered alongside many other factors, which ultimately made a categorisation of

informants by the adventitious/congenital nature of their sight loss moot for the purpose of this research.

First of all, as explained in the section 'visual impairment: the disease' (1.4), the variety of ophthalmological conditions and their manifestations and development make it difficult to draw a clear line between adventitious and congenital sight loss. Secondly, a family environment fostering or stifling the independence of the visually impaired person has an important impact on the possible worlds that that person may see herself as capable of inhabiting, regardless of whether she is an adult or a child. The type of education received and the setting in which it was received (a mainstream or a special school) can have a similar influence. Moreover, although it may be assumed that adventitious visual impairment is more disruptive to one's biography than congenital visual impairment, some of my congenitally visually impaired participants recounted how their sight loss had caused a 'biographical disruption' (Bury 1982) at a later point in their lives. For instance, a deterioration of their already impaired sight may have brought about medical retirement. In sum, it is difficult to untangle the complexity of the factors that may influence the self-efficacy, aspirations and, importantly, the life narratives of visually impaired people. This thesis seeks to harness the diversity of life experiences of my participants because, in spite of the fact that they drew my attention to the importance of the difference between congenital and adventitious sight loss, ultimately this difference emerged as only one of multiple factors.

1.3 Terminology

In this thesis I use the terms 'visually impaired people' and 'people with sight loss' interchangeably in order to refer to both blind and partially sighted individuals. Although 'blind' and 'partially sighted' have been officially replaced by 'severely sight impaired' and 'sight impaired' respectively (RNIB n.d.b), 'blind' and 'partially sighted' are still more commonly used. In the world of disability, a particular effort has been made in order to avoid words that may seem disparaging (Groce 2019:156). The terms 'visual *impairment,*' 'sight *loss*' and '*dis*ability' all have a negative connotation. The fact that sight can be 'impaired,' rather than different, should not be taken at

face value. The same can be said about sight 'loss.' People with no sight at all have been at the centre of many thought experiments but, as Georgina Kleege points out in an ironic paper on the 'hypothetical blind man' (Gitter in Kleege 2013:447), they are extremely rare (Kleege 2013). Even apart from this, adopting uncritically the concept of loss in this context can be problematic, as the quote from Sargy Mann at the beginning of the thesis suggests (see also Kleege 2017 and Trevor-Roper 1988[1970]). Likewise, 'dis-' suggests lack, and dis-ability eclipses the ethos of this thesis, which is to shed light on the *capa*-bilities of visually impaired people. With these reservations, I will use these terms throughout the thesis in order to be faithful to my participants' own terminology.

Considering the use made by the visually impaired community of expressions such as 'sight *loss'* and 'visual *impairment*,' a study of sight loss differs from one on hearing loss: the expressions hearing 'impairment' and hearing 'loss' may hurt those who see themselves as forming a separate culture. An analysis of the reasons why visual impairment has not given rise to the same culturalization of this sensory deficiency (which is another problematic term), is beyond the scope of this thesis, although the fact that visually impaired people can communicate with the non-visually impaired by using the same language (unlike people with a hearing impairment, who may use a common language, sign language, see Groce 1985:104–105, Fjord:1996) may be significant. Even though I deploy terms that may be seen to have a negative connotation, in the conclusion I attempt to lay emphasis on common humanity in order to overcome the division between the two artificial polar opposites of sightedness and sightlessness. In other words, I endeavour to supersede the equation between sightedness with normality.

Apart from terms that may have a negative connotation described above (such as sight loss), visual expressions used in daily language, such as 'I'll see you tomorrow,' are so numerous that they are difficult to circumvent, and indeed I found they were commonly used by visually impaired people themselves. One participant even told me that it would be discriminatory not to use these expressions with visually impaired people, as this would make them feel different. Besides, the metaphoric meaning of such expressions has become so prominent that the fact that a blind person may not actually see you tomorrow becomes irrelevant. One of my

participants, Yussef, to whom I dedicate a portrait, uses 'vision' referring to a deeper, more profound way of seeing his direction in life, while he reserves the use of 'sight' to the physical capacity to see. Apart from this, during my fieldwork I did not notice the use of particular optical metaphors by my informants, and the use of visual metaphors in this text ('refocussing the self', 'looking forward') is my own. I believe that, on one level, these phrases are so common that they can be understood by my participants without problems. On another level, I feel that presenting the reader with a choice of vocabulary that apparently jars with the subject matter of the thesis may help break the stereotype of the existential blindness of the blind man. I hope this approach will foster an overcoming of trite stereotypes — or, to say it metaphorically, images. After all, sight as a metaphor is a domain where all humans can meet, regardless of their visual acuity or the breath of their field of vision.

1.4 Visual Impairment: The Disease

In his seminal work, Arthur Kleinman distinguishes between disease and illness. Disease is the decoding of the subjective illness into a biological pathology, as done by a medical doctor (Kleinman 1995:32). Illness is the sickness as perceived by and given meaning by patients, as influenced by their social network. It is psychosocially determined and has repercussions not only on the patients' lives but also on those surrounding them (Kleinman 1980:72–73)[7]. In this section I briefly present visual impairment in the UK as a medical issue, i.e. as a disease. In this chapter I also outline the roles that the Government and non-profit organisations play in the lives of visually impaired people in this country at a macro level. While the former tends to affect the lives of visually impaired people in a structural, impersonal way, the latter also play a role of the daily lives of people with sight loss, and I will expand on this in next section.

There are approximately 350,000 people registered as visually impaired in the UK, evenly split between blind and partially sighted (RNIB 2018). Among them, the

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[7] Compare this distinction to the one between 'chart talk' and 'narrative reasoning' (Mattingly 1998b).

leading causes of sight loss are: age-related macular degeneration (48%), glaucoma (16%), cataract (12%), retinitis pigmentosa (10%) and diabetic eye disease (8%) (ibid.) It should also be considered that different ophthalmological conditions may present together, the same condition may manifest differently in different individuals, the field of vision may be affected in the same way (for instance by tunnel vision) by different pathologies and, most importantly, that sight loss can progress or, less frequently, regress, and change in quality or degree during the life of the patient. Besides, visual impairment may occur alongside other types of pathologies or disabilities, including learning disabilities. Within a strict interpretation of the social model of disability (Barton 1996:8), people affected by such medical issues are merely impaired: they become disabled only when society restricts them in some way because of their impairment (Hunt 1966 in Barnes 1996:46). However, I concur with Ginsburg & Rapp in saying that the demarcation between the two is too complex (2013:54), and in the thesis I use the terms 'disability' and 'impairment' interchangeably. Similarly, the expressions 'person with a disability' and 'disabled person' refer to the objective nature of the impairment and the role played by society in making such impairment a disability respectively (Dijani in Keating & Hadder 2010:116–117) and, for the same reason, I also use them interchangeably. I am aware that the latter term, which is incidentally used by major UK charities such as Scope, Disability Rights UK and Leonard Cheshire, may be perceived as disparaging. However, I hope that the spirit of the thesis counters any negative connotation that it may carry.

Whether a person meets the criteria to be registered as 'severely sight impaired' or 'sight impaired' depends on her visual acuity and field of vision, which are assessed by a consultant ophthalmologist (RNIB n.d.b). If she does, she will be issued a certificate of visual impairment (CVI) (ibid.).[8] Holders of this document have the right, though not the obligation, to register with their local authority (NHS 2018). Those who decide not to register can still receive information and support from their local authority, while those who do register can receive different types of concessions, such as the 'blind person's tax allowance' and the 'television licence fee reduction'

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[8] In England and Wales; the certificate is called differently in Scotland and Northern Ireland (NHS 2018).

(RNIB 2020). Moreover, they are in a better position when claiming welfare benefits, most of which are being replaced by Universal Credit (ibid.). Visually impaired people who are in employment, who are currently only one fourth of all registered blind and partially sighted people of working age in the country (RNIB 2018), can apply for support at work through Access to Work (Gov.uk n.d.a).[9] This scheme, which is run by Jobcentre Plus, issues grants to pay for a support worker, special equipment or travel costs, among other things (RNIB n.d.a). People with sight loss that apply for a job may refrain from disclosing their disability (NHS 2018), although doing so may entail either simply postponing the disclosure, or not being offered the reasonable adjustments during recruitment to which they are entitled under the Equality Act 2010 (Gov.uk 2015). In fact, according to this act, disability is one of the 'protected characteristics' on the basis of which an individual should not be discriminated against 'in the workplace and in wider society' (ibid.).

Besides the regulatory framework and the state programmes briefly described above, visually impaired people can contact their local authorities, in particular their social services' sensory team, who can assess their needs and provide different kinds of services. Moreover, there are charitable organisations that offer support to people with sight loss: the Royal National Institute of Blind People (RNIB) is the main one in the country, but there are many other not-for-profit bodies active in Donchester. All charities combined offer information on or help with a wide range of issues, including mobility, one of the main skills affected by ophthalmological conditions, and employment.

1.5 Visual Impairment: The Illness

A great number of ophthalmological and non-ophthalmological conditions can affect people's sight. This, compounded with the diversity of life experiences of people with sight loss, explains the plethora of life situations in which they may find themselves. Moreover, according to Kleinman's definition of illness (1995:32), the interpretation of the disease by various social actors (the patient herself, her family, etc.), unlike the

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[9] The Gov.uk website does not specify whether registration is required in order to apply for the scheme (Gov.uk n.d.a); there is a different system in Northern Ireland (ibid.).

monolithic medical diagnosis of the disease, is multiple. In spite of this multiplicity, the difference between congenital and adventitious sight loss is an emic criterion frequently deployed by visually impaired people to create two broad categories of visually impaired people and to contextualise their own experience of sight loss. Adventitious and congenital sight loss are categories that should be taken into consideration in a social discussion of visual impairment, because they help explain why certain individuals may be more or less adapted to their sight loss. Nevertheless, they remain abstract categories that hide the complexity of this sensory impairment. For instance, some individuals may have had some sight at birth and the process of degradation may have been far from linear. Moreover, even people classified as blind may retain some light perception, but may do so in a way that is different from that of another blind person.

The temporality of sight loss can be a useful lens through which to look at the distinction between disease and illness, which is at the heart of Kleinman's theory and one of the tenets of medical anthropology. For instance, the medical examination following which the Certificate of Visual Impairment is issued is conducted at a point in time while, from the perspective of the patient, the registration is only one of the multiple steps that they may take after losing her sight. This tangible document, so important to prove the advent of sight loss from an administrative perspective, neglects the temporal trajectory before and after medical diagnosis. In sum, it erases the complexities of adaptation to visual impairment happening later in life, to which I will try to do justice in the portraits of Dietlinde, Sam, Andy and William, all of whom began their life as sighted.

Even though, as explained above, my participants commonly used the words 'visual impairment,' disability' and 'sight loss,' some of them may consider sight loss as a condition *tout court*, not as a medical condition, and may object to calling it an 'illness,' as well as a 'disease.' I will, however, use the word 'illness' strictly in the sense meant by Kleinman, which focusses on the meaning that a socially situated individual attributes to a medically disruptive life event. In other words, it refers to 'the patient's problem' rather than to 'the physician's problem' (1988:136). I believe it is accurate to use this term inasmuch as, on the one hand I have never come across people who did not consider the advent of sight loss as a problem, and on the other

hand that the meaning created by the person can indeed mitigate such perturbing event by turning it from a medical condition to a condition. Narrative is part and parcel of the meaning-making in illness theorised by Kleinman: 'The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering' (ibid:49). Again, the fact that it is controversial to label a visually impaired person a 'patient' is testimony to the power of narrative to guarantee a person 'selfhood without sameness' (Ricoeur 1992:116), i.e. to make a person whole again after a life-changing diagnosis.

1.6 Literature Review: Visual Impairment

Thanks to its attention to the patient's lived experience, medical anthropology has a great potential to contribute to the study of visual impairment, just as it has contributed, though belatedly (Devlieger 2018b:2), to the study of disability in general (Reid-Cunningham 2009:103, see also Groce 2018a and Kasnitz & Shuttleworth 2001). Nevertheless, the literature on visual impairment in this branch of the discipline, and in the discipline as a whole, is scant. This literature, although limited, nevertheless warrants a brief review. This review will also include texts that are not relevant to the present thesis, and that will not be cited again.

The most notable ethnography on people with sight loss is Shlomo Deshen's *Blind People: The Private and Public Life of Sightless Israelis* (1992). Deshen, who incidentally is sighted, carried out his research between 1983 and 1985 among blind[10] people in Tel Aviv who had lost their sight in their teens or earlier (ibid:6–7). His monograph spans various facets of the lives of his informants, and its chapters are presented in the order of the ever-larger social circles to which they pertain: from the body to the family, from the workplace to the nation. His analysis focuses on the socialization of blindness, and it highlights how this phenomenon starts within the family: blind children are encouraged by their parents to pursue less desirable careers and marriage partners than those of their sighted peers (ibid:37–48, especially ibid:38, see also Deshen 1987). The present thesis is not structured so as

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[10] His criterion for recruiting participants was that they should require 'one of the standard mobility aids when travelling' (Deshen 1992:7).

to cover all the issues dealt with by Deshen, and rather focusses firstly on therapeutic emplotment and secondly on work. However, it is based on interactions and conversations with visually impaired people on a very broad range of life domains. It therefore aims to complement Deshen's work by presenting what is at stake for a visually impaired population in a 21st century English metropolis. The choice of work and therapeutic emplotment as issues to give importance to is, in fact, a research finding in itself.

The other main monograph on blindness is John L. Gwaltney's *The Thrice Shy: Cultural Accommodation to Blindness and Other Disasters in a Mexican Community* (1970). As the title suggests, the author, like Deshen, points out the socially conditioned attitude that blind people in that particular Chinantec community have towards their disability: they consider sight loss as a divine punishment (ibid:101–105), and pain as a cross to bear (ibid:105–106). Gwaltney presents their resignation vis-à-vis their sight impairment, but also the other life struggles that plague them in their rural Mexican locale, such as crop failure. The uniqueness of Gwaltey's contribution to the anthropology of blindness is twofold: he was blind himself, and parasitic onchocerciasis was endemic at his field site, which meant that sight loss was very common. The challenges he faced as a blind ethnographer add a layer of complexity to the accommodation to the field that is part and parcel of field research (ibid:161–171, cfr Steiner 1994). The pervasiveness of this ophthalmological condition in the area, in its turn, presents a peculiar setting from a social as well as from a medical perspective. Gwaltney's book is true to the spirit of anthropology monographs in its comprehensiveness, but such comprehensiveness is due to his attention to the various aspects of the lives of people in this community. It falls short of giving an in-depth account of visual impairment at the Chinantec community, to which only one chapter is devoted, and it will therefore not feature in my discussion.

Socialization is again the focus of Scott's *The Making of Blind Men: A Study of Adult Socialization* (1981[1969]), which was carried out in the American context. This book, which is based on mixed methods including interviews (ibid:11–12), is highly critical of charitable organisations. They are, in Scott's view, responsible for preaching a restorative approach to sight loss, i.e. one aimed at social integration, while practicing an accommodative approach, i.e. one that makes blind people the

passive recipients of charity (ibid:80–90). This, he contends, benefits both charitable bodies themselves and society at large, which is happy to find consenting parties upon whom to bestow its kindness (ibid:93). Charitable organisations feature prominently in the lives of many of my participants; indeed Sunshine is one of them. Preoccupations regarding the way in which some charities operate and the leading role of sighted people in them were voiced by my participants. However, my participants' conversations on charities did not foreground the role that such bodies may play in making visually impaired people more passive. Still, I believe there are a few questions worthy of separate research projects, which could be informed by Scott's work. Considering that the charity model of disability has been broadly superseded by the social model in the international discourse (Groce 2018a:1–2), why is the term 'charity' (in the sense of charitable organisation) still widely accepted in British society? After all, empathy is publicly promoted over sympathy, and a lot of importance is given to semantics in promoting a more equitable environment for all (see for instance of the use of the singular 'they'). I will use the term 'charity' myself out of conveniency, and with the hope that it will appear dated to those who may read this work in the near future. Moreover, is the fact that so many sight-loss non-profit organisations do not fund scientific research to prevent ophthalmological conditions a sign that they practice an accommodative rather than a restorative approach, to use Scott's terms? These are all topics that deserve further research.

In more recent times, anthropologists have singled out particular aspects of the lives of people with a visual disability as worthy of exploration. For example, like Deshen in an Israeli context, anthropologist Gili Hammer studied blind women's appearance management (2012, 2016), her own positionality as a sighted researcher (2013), as well as the relationship between tandem riders with and without sight loss (2015). She also discussed the sensorial nature of the transmission of medical knowledge (2017). In Britain, the first of these publications resonates with Nili Kaplan-Myrt's paper on the body image of blind people, mostly adolescents (2000), while the third is in line with Karis Petty's chapter on visually impaired ramblers (2015). In an international context, an example of how visual impairment can cause culture-

specific issues[11] is shown by Nayinda Sentumbwe's study of the difficulties in finding a husband encountered by blind women in Uganda, a situation exacerbated by the fact that blind girls are overprotected and not taught to do household chores (1995:166). Within medical anthropology, Sandra Lane's work on sight loss in Egypt is worth mentioning for her analysis of the discrepancy between medical and local definitions of disability (Lane et al. 1993) and of the different factors influencing the 'hierarchy of resort' pursued by people affected by eye disease (Lane & Inhorn Millar 1987).

From the above review of the literature, it is apparent that anthropology has not reached its full potential in studying visual impairment. The present qualitative study, based on participant observation and interviews, aims to partly fill this void in two ways. Firstly, it shows the narrative 'work' that visually impaired people put into emplotting their lives in a way that is therapeutic and that may subtly transform the public's perception of disability. Secondly, it looks both at the role that professional work plays in this, and at what counts as 'work' when employability is jeopardised by visual impairment. These two areas of inquiry, narrative and work, will be put in the context of their respective bodies of literature in the following two sections.

1.7 Narrative

Among the different types of 'work' I encountered among visually impaired people, I was most struck by the narrative 'work' they carried out on themselves in order to cope with their visual impairment. Besides the logistical adaptations they had to perform, which is in itself another type of 'work,' they found themselves having to reconceptualise their life narratives in a way that was, eventually, therapeutic. This section is not a literature review; it rather clarifies what I mean by 'narrative' and 'emplotment,' and brings into play authors who, in disciplines as different as philosophy and anthropology, have dealt with the question of how we emplot our lives, and how we may do so therapeutically in the face of a medical crisis.

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[11] Outside of the remits of anthropology, see also Bevan-Brown & Walker 2013 on the participation of Maori people with sight loss in community activities.

In this thesis, I use the terms 'narrative' and 'story' interchangeably to refer to specific stories, which are the temporally, though not necessarily chronologically, structured rendering of a selection of events. I speak of 'stories' because I refer to the 'creative telling of a life' (Lamb 2001:16), as opposed to the factual, verifiable unfolding of events, which I call 'histories.' Many of these stories have a more or less explicit meaning or moral for the individual creating them. I use the words 'narrative,' 'narrativity,' 'narrativization' and 'emplotment' interchangeably to refer to the broader process whereby particular narratives/stories are created. Stories can be formulated orally for the benefits of a listener or an audience, but can also be tacitly harboured within a person.

It has been argued that narrative is situated at the intersection of the personal, the social and the historical (Riessman 2002:697). This thesis presents the social issues that emerged during my fieldwork, but also sheds light on some individual participants by adopting a biographical approach. Narrative is at the heart of the latter side of the debate, i.e. the biographical one, as it becomes apparent in the 'portraits' I wrote on some informants. However, narrative is also at the heart of the former aspect of the debate, i.e. the social one. Stories are not created in a void space, but in a specific socio-cultural context, which helps to shape them, and which they, in turn, affect (see McAdams 2006). In my research I found that my informants' narratives, albeit unique, could be subsumed under different pattern types (restitution, chaos and quest narrative (Frank 1995), overcoming narratives and narratives of competence (Bloom 2019)), and that narrativization was the thread linking my three groups of research participants. Individuals like William, Andy, Yussef and Dietlinde created narratives to re-craft their lives in the face of sight loss, as did the users of the charitable organisation, as did the workers at the factory. Importantly, narrative was not superposed onto, but embedded in experience, which was itself shaped as narrative (Bruner 1991, Bruner 2004, Mattingly 1998a, Mattingly 2000:182, see also Lamb 2001:16). Before leaving Spring, Jim was already planning to continue to be as active as a pensioner as he had been as a worker. Sam's struggle was not one that he talked about post-factum, but something that he did constantly, just in order to get through his day.

Throughout the thesis I use the word 'self' in the sense of 'locus of experience, including experience of that human's own someoneness' (Harris 1989:601) because my focus is on my participants' personal stories. Whenever their lives, and the narratives that spring from them, have at their heart an 'action purposively directed towards a goal' (ibid:602), I use the term 'self' to refer rather to their personhood, i.e. to their 'interconnected agentive capacities' (ibid:603). In fact, my participants are naturally affected by their social environment, which influences them and which they, in their turn, help transform. It will be clear from the context whether the emphasis is on a 'self' defined in the strict sense of the term or in its more relational manifestation. Indeed, the separation between self and person is permeable (ibid:608). The 'self' I describe is also 'extended in time' (Neisser 1988:46–50), as it is characterised by memories and anticipations, i.e. by a temporal dimension, which is intrinsic to narrativity. It is also 'conceptual' (ibid:52–54), i.e. constituted by the plethora of qualities, roles and attributes that the subject, as situated in a social context, attributes to themselves. My participants may see themselves as 'visually impaired,' but also as 'colleagues,' 'friends' and so forth. Finally, the self I present in the thesis through the lives of my participants appears as self-crafting and 'agentic' (Sökefeld 2001:539), and has a lot in common with the modern individual described in the literature as caught between uncontrollable risks and the capacity to shape one' existence as a life-project (Giddens 1991:148, 179). Agency is central to such modern individual, and it has been argued that 'successful (healthy, appropriate) identity in a modern postcolonial context is less a self-characterizing narrative with a mirroring world than a sense of command over narrative complexity: narratives which one has to some extent chosen, whose mastery gives one a sense of direction' (Luhrmann 2001).

In this regard, helpful insights come from psychology (Choler 1982) and, more importantly, from narrative theory. Paul Ricoeur argues that an individual faces a conundrum when trying to subsume all their different life experiences under a coherent self. He thinks narrative provides a solution to this problem by allowing the person to emplot their different selves at multiple points in time into a single story (1992:140).[12] In other words, thanks to emplotment, permanence in character can be

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[12] Cfr Ewing 1990 on how we preserve wholeness in spite of conflicting narratives.

preserved even in the absence of permanence in time (ibid:124). A person finds her sense of self not in her changing, aging body, but in the capacity to identify herself as the entity to which that changing body belongs (ibid:129). He also contends that, with some reservations, life can be modelled upon and explained by narrative conventions because every person is author of their lives (ibid: 160–161). Along similar lines, Jerome Bruner argues that there is no such thing as life fixed in the past: life is inseparable from its later interpretations, which are produced as it is told and retold (2004:708). Ricoeur also focusses on the agency of the teller: even if we cannot totally 'write' our lives, by telling our life stories we can co-author their meaning (1992:162). Whenever we find it difficult to cope with the elusive nature of what happened to us, fiction offers help by organising life retrospectively (ibid.)

The anthropological literature situates individual emplotment within a particular society, and is rich in examples of the benefits a sufferer derives from emplotting their situation within a particular cultural, often ritual, context. Claude Lévi-Strauss, for instance, describes a Cuna shaman helping a woman in childbirth by mobilising the local cultural imagery (1963:186–205, see also Dow 1986 and, outside of anthropology, Hutchinson & Moerman 2018, Moerman 2012, Nichter 1981). Within medical anthropology, Cheryl Mattingly situates herself in the same tradition as Ricoeur (see for instance Mattingly 1994:812–813), and coins the term 'therapeutic emplotment' (1994), which echoes Kleinman's 'illness narrative' (1988). Mattingly argues that meaning-making can be deployed to ease distress in quite mundane medical settings, where patients and medical practitioners weave stories in concrete life situations (1994). In her ethnographies, she describes therapeutic emplotment as the reframing of a clinical encounter into a meaningful interaction between practitioner and patient. For instance, she shows how a simple walk along a hospital corridor can be interpreted as a tour by the occupational therapist and the head-injured patient she is assisting (ibid.).

The concept of therapeutic emplotment has been deployed and developed by other medical anthropologists (e.g. Calabrese 2013, DelVecchio Good et al. 1994, Kohn 2000, Mattingly & Lawlor 2001). If we include publications that do not explicitly mention 'therapeutic emplotment' but that deal with how people use narrative (in text or images; online, off-line or in the body) to therapeutically reframe their lives in the

face of a medical problem, the literature is even vaster (see Benton, Sangaramoorthy & Kalofonos 2017; Levy & Storeng 2007; McMullin 2016; Miles 2009; O'Loughlin, Arac-Orhun & Queler 2019; Samuels 2016; Vanthuyne 2003). The concept of therapeutic emplotment is central to the whole thesis, where I show how retracing one's life trajectory can help reframe a diagnosis of visual impairment in a therapeutic way. In particular, in chapter 5 I draw on Arthur Frank's *The Wounded Storyteller* (1995) to point out that the narratives that my participants constructed and lived by were quest narratives (ibid:115–136), rather than restitution narratives (ibid:75–96): sight loss was not an obstacle they overcame to go back to their previous life. On the contrary, it was seen as a trial that led to a more meaningful and, in a way, a more moral existence.

If moral meaning is the soul of history, which, unlike the chronicle, seem to demand a sense of closure and purpose in the narrative (White 1981), so it is essential to personal stories. In fact, Mattingly's further contribution to the notion of therapeutic emplotment is her emphasis on morals as pivotal to the stories created by patients when they therapeutically emplot their lives (1994:820–821). Philosopher Charles Taylor, who also believes we must understand our lives in narrative form (1989:52), like Mattingly emphasises the connection between self and morality: he argues that 'a moral reaction is an assent to, an affirmation of, a given ontology of the human' (ibid:5), and that the self cannot be conceived of in isolation: it only exists in reference to questions on the nature of the good that we orient ourselves by (ibid:50). In sum, 'to know who I am is a species of knowing where I stand' (ibid:27). More fundamentally, Taylor contends that it is not possible for a person to live outside of a framework by which to orient themselves in their moral choices (ibid:31). Furthermore, he attributes to these moral choices (in particular to 'hypergoods,' i.e. the highest-ranking value in a person's life) a decisive role in determining who a person is (ibid:63). The present research offers valuable insights into the nexus between 'what really matters' (Kleinman 2006) in one's life story on the one hand and 'work' on the other, insofar as it presents the stories of various people who re-oriented their personal and professional trajectories in a way that was more genuine and meaningful to themselves and more benevolent towards others. If one's engagement in professional work has long been recognised to be an important constituent of one's moral self and self-image (Beck 2000[1999]:10, see also Howe

on unemployed men in Northern Ireland 1990:145, 215), my participants demonstrate that other types of 'work' can foster a self that is equally, if not more attuned to their values.

Many stories of self-transformation have appeared in the form of biographies. Those on people with sight loss have an emphasis on their achievements (see for instance Stuckey 1995 and Freeberg 2001), as have autobiographies by visually impaired people. It has been argued that autobiographies offer the reader the opportunity to see the social in the personal (Barrett 2014:1570), and I indeed deem them helpful to understand disability as a social phenomenon. Autobiographies by disabled people are an established form of life narrative (Couser 2013). What is peculiar to autobiographies is that writing them may be a way to instill a transformation in the author themselves (a way of 'life making' Bruner 2004), as well as a way to plant seeds of transformation in others (see Fabre, Massenzio & Schmitt 2010:86). As there is always a turning point in an autobiography, each autobiography is the story of a conversion (ibid:93). The converted is also a special witness, as his life encompasses the before and the after, and like the author of any autobiography presents the transformed self (ibid:99–101). I am aware of the critique formulated by disability studies scholars, according to whom temporal references such as 'before,' 'after,' '*advent* of disability' may underpin the view that disability is a loss (Kafer 2013:42–44). My rationale for deploying these terms is that I did find evidence of disability as a watershed moment, in particular among adventitiously visually impaired participants. Although my thesis maintains this division semantically, it does counter the equation of disability and loss through the stories of many informants. Although it is true that sighted people normally do not hope to become visually impaired, it is true that 'the "after" self' may long for something different than 'the time "before"' (ibid.).

I should point out that in my research I found that, although narrative 'work' was particularly intense among people with adventitious sight loss, it was not exclusive to them: born blind or born visually impaired individuals may also have to perform it when their disability has to be negotiated, either because their sight impairment has progressed, or because they encounter a new social or professional environment. As Hector Chevigny and Sydell Braverman have pointed out, the 'adjustment of the

blind' is not only a physical adjustment to one's disability, but also the adjustment to new social situations (1950:11, 19). This was even more true considering the cultural context of Donchester, where it is difficult to admit one's setbacks, regardless of whether they are caused by a medical problem or by another factor (Frank 1995:63).

Narrations of the self often crystallise in the literary genre that, as mentioned above, makes manifest the temporal development of the emplotted self: the autobiography. There are multiple examples of autobiographies (or autobiographical accounts) among visually impaired people (e.g. Blunkett & MacCormick 2002[1995], Clark 1977, De Montalembert 1986[1982], Giles 2010, Hull 1997[1990], Keller 1951[1903], Kleege 1999, Sullivan & Gill 1989, White 1999, Whitehouse 1990, see also Malti-Douglas 1988), as well as among disabled people in general (e.g. Frank 2000), and disabled anthropologists (e.g. Murphy 1990). None of the visually impaired people portrayed in this thesis has written an autobiography. However, some of them demonstrate a similar love for sharing their life experience through autobiographical narratives. Yussef (chapter 6) does so explicitly through public speaking, while William (chapter 5) does so more implicitly through his storytelling, and all of them did it, to a greater or lesser degree, by taking part in my doctoral project.

Although Yussef and William appear on stage, it would be more correct to say that they take their message to whomever crosses paths with them and is willing to listen. In my interactions with them and with all of my participants I could sense that they were akin to the craftsman described by Richard Sennett (2004[2003]:83–89). They plant a seed of transformation in others by performing their 'work' continuously, repeatedly and quietly, which is the only way to instill change in others without arising envy (ibid:87). They induce change in those who are willing to listen to their stories, and in those who simply take the time to experience the 'work' they do in their minor and major challenges. Were they to impart their teachings through 'mastery over others' (ibid:83), such teaching would be written in stone, a statement imparted by someone who savours the 'satisfaction of being right' (Auden 1976 in ibid:84). As craftsmen engaged in multifaceted 'work,' though, my participants 'make a thing well' (2004[2003]:84), and what that thing may become is left in the hands of the recipients of their message, who may even 'imagine another version of themselves' (ibid:36). As I will argue in chapter 6, the therapeutic emplotment that

visually impaired people craft for themselves by weaving together many strands of their lives, including their visual impairment and the non-professional type of 'work' they perform, may then be spread in order to effect a positive change in others, sighted or non-sighted alike. What use would it be to whisper to the mirror 'It is this darn illness that has given me that second chance' (Kleinman 1988:143)? By saying it or demonstrating it to others, the fruits of a successful therapeutic emplotment are shared among a broader social group. In fact, towards the end of my thesis I will also address, and supersede, the question of whether my authorial voice interferes with the voices of my participants. I will explain that stories are always co-constructed (see Frank 1995:131 on self-*other* stories). Indeed, I will argue that the co-constructed-ness of my participants' narratives by themselves and their interlocutors, among which I include myself as a researcher, is what makes them especially therapeutic.

1.8 Work

This thesis contributes mainly to the anthropology of visual impairment and to the anthropology of therapeutic emplotment. However, it also draws on the anthropology of work when it informs the discussion on the two main facets of work relevant to the narratives of people with sight loss. With the term work without inverted commas I refer to the professional side of work. The title of the thesis reveals a subtle, bitter irony: a disproportionate number of visually impaired people are unemployed or underemployed in spite of the various personal and interpersonal qualities they have developed by performing an incredible variety of meaningful 'work.' The 'work' (between inverted commas) of people with sight loss consists of various facets. One is the negotiation of their belonging to the visually impaired community, which I deal with in chapter 2. Another facet of 'work' is the extra time and effort that people with sight loss may have to put into carrying out activities of daily living. This will emerge throughout the thesis. The most salient type of 'work' discussed in this thesis, however, is the narrative 'work' that people with sight loss put into emplotting, i.e. narratively restructuring, their lives in a therapeutic way in the face of sight loss.

Below I present an overview of relevant literature on work as employment, with a focus on disability studies and medical anthropology; further below I clarify the definition of 'work' by drawing on apposite sociological and anthropological literature.

1.8.a Work as Employment

If people affected by very diverse types of disability can lament a reduced employability (see Grint 1998:37 and Groce 2018b:e724), visually impaired people also have to confront the image of the 'blind beggar,' which has been forged in Western thought over centuries (see Caeton 2015:34–35, Deshen 1992:74).[13] There is a grain of truth in this image: even in the late 20th century begging was the most common form of employment for disabled people worldwide (Groce 1999:756, see also Groce, Loeb & Murray 2014). That being said, the entrenched stereotype of the blind beggar had, particularly in the past, profound implications for blind people: the price they had to pay for being recipients of any form of charity was having to admit their inferiority (Chevigny & Braverman 1950:177) and, even when accommodated in specifically created institutions, the blind asylums, they were supposed to remain idle (ibid:86). Of all the different stereotypes associated with blindness,[14] passivity and dependence are perhaps the most enduring. Blindness has connotations of lack of 'independence, intellectual acumen, morality, and productivity' (Caeton 2015:36). There is evidence that the association between blindness and incompetence persists among employers (McDonnall et al. 2019), and that this is countered only by exposure to over-performing blind individuals (ibid:350). Besides, because nowadays a good proportion of the visually impaired population are elderly (according to the RNIB, 1.2 million of people with sight loss in the UK are aged 75 or over, RNIB 2018:6), and because old age is itself associated with these stereotypes (see Lamb 2018, and Lynch 2012:12-18 on the cultural construction of ageing in America), sight loss is associated with lack of independence (Chevigny & Braverman 1950:294) and, like all disabilities, contravenes 'all the values of youth, virility, *activity* and physical beauty' (Murphy 1990:116, my emphasis) that our society treasures. These

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[13] For a more comprehensive history of blindness in the West see Barasch 2001, for a history of the blind in French society see Weygand 2009.

[14] See Kleege 2013 on the 'hypothetical blind man,' the born totally-blind individual used by philosophers in thought experiments.

stereotypes are the most relevant to this study, as helplessness and dependency are in stark contrast to the productivity associated with work, a 'valued attribute' (Groce 1999:756) in our society.

A review of the recent literature on visual impairment suggests an interest of disability studies researchers in discrimination in the workplace (Victor et al. 2017), difficulties encountered because of multiple disabilities (Ehn et al. 2016, Hierholzer & Jacquelyn 2017), and the transition between education and employment (Antonelli, Steverson, O'Mally 2018). Professional rehabilitation (Crudden, McDonnall & Sui 2018) and the better health enjoyed by people in employment (Ehn et al. 2016) are also examined. Generally speaking, however, it is the authors of the three main anthropological works on visual impairment mentioned in the previous section that offer the most insightful comments on the topic of professional work. I will deal with them in turn, and also present the contribution of visually impaired academic Sally French, who researched the vocational histories of visually impaired people in Britain. Poverty and dependence (1970:110), as well as reliance on begging as a source of income (ibid:112), characterise the community described by Gwaltney. Employment is, though perhaps not explicitly so, pivotal to Scott's study, as the accommodative approach (1981[1969]:93) may result in unemployment and underemployment. Deshen, in his turn, devotes a chapter of his book to 'seeking employment' and another one to 'the work experience.' In the former, he argues that the limited number of professional pathways opened to visually impaired people is due to an underdeveloped free market economy in Israel, and to a lack of government initiative to practice positive discrimination (1992:63). He presents the dire future of those few blind people who do not pursue a career as an assembly worker in a sheltered workshop or as a switchboard operator, which are the most typical professions for people with sight loss at his locale (ibid:65). Following their academic training, they often have to come to terms with an unchallenging job (ibid:66), and pursuing work 'beyond the preserves of the blind' seems unachievable (ibid:68). In his chapter on work experience he reiterates the limited professional chances open to visually impaired people (ibid:73), as well as their frustration at their own situation (ibid:73). Deshen also addresses issues pertaining to blind workshop workers and switchboard operators, such as the devotion of these workers even in the face of boredom (ibid:74) and the importance they attribute to the immaterial

gains of the job, for instance dignity (ibid:76) and access to wider social circles (ibid:79). These features merge with those of the broader definition of 'work' which I will explore below, and resemble those I encountered on the shop floor at Spring, which will be discussed in chapters 3 and 4.

A further contribution to the social study of visual impairment and work is Sally French's. In her book on visually impaired physiotherapists in Britain (2001), she argued that, in this country, the link between this profession and this particular sensory disability was historically reinforced by the existence of a school of physiotherapy for visually impaired people (ibid:64). French's work reveals the ambivalence felt by this professional group. On the one hand, most of her informants state they would not have pursued this career had they been sighted (ibid:80), which echoes the lack of opportunities described by Deshen's participants, as well as his more ambitious participants' failed desire to shun professions historically associated with blind people (see how such failure is emplotted: 1992:79–80). On the other hand, French's informants regard their profession as a way of contributing to other people's lives, which they say they normally find very difficult to do as visually impaired people (2001:149). Some people in minority groups are channelled towards careers that are socially pre-established for them, and some have resisted entering this (see Henry 1995:286–287). Visually impaired people have historically been directed towards specific occupations or occupational settings. These are different in different countries (Keating & Hadder 2010:124), and the British blind workshops are a clear example of this phenomenon. At the same time, though, it appears that a stereotypical career and a meaningful career may not be mutually exclusive (cfr Reily & Cardoso de Oliveira 2017), and I will elucidate this when presenting Spring (chapters 3 and 4). French's more recent work is an excursus on visually impaired people and work from the 18th century to the early 21st century (2017). She presents an historical overview of the issue of employment for visually impaired people. She also presents the stories of the working lives of 50 visually impaired British people, including her own. By contextualising the careers of a small but diverse sample of visually impaired people within their broader life experiences, the present study will add some depth to her research on the most recent developments of employment for people with this sensory disability.

It is apparent from the body of literature on visual impairment and employment presented above that the actual *meaning* of employment for people with sight loss is only marginally addressed. I aim to address it in chapters 3 and 4, based on my fieldwork at Spring, and in chapter 5, based on my fieldwork with individually recruited participants. Furthermore, the authors cited, with the exception of Deshen, have compartmented the professional from the other life spheres, thus failing to capture the interconnections between self and professional self, between work and 'work.' These interconnections are fundamental when elucidating the *therapeutic* role of employment in the lives of people facing sight loss, and job loss. This role is one of the threads of this thesis, and I will now expand my literature review to texts tackling the nexus between illness and employability in fields other than visual impairment.

The medical anthropology literature has often focussed on the negative aspects of the nexus between work and wellbeing. Some scholars, for instance, have drawn attention to the negative correlation between illness and employability (see for instance Alcano 2009, Hay 2010, Jaye & Fitzgerald 2012). An article on a more specific case is the diary-style recount of the tribulations of a narcoleptic at her workplace (Eugene 2013). Moreover, some anthropologists have analysed the negative repercussions that harsh working conditions, alongside other structural factors, have on transnational migrants on both sides of the border (Holmes 2013, Unterberger 2018). Others have shown how a disease can constitute an 'idiom of distress' (Mendenhall et al. 2010) and how the malaise caused by the introduction of neoliberal practices in the workplace can be expressed through medical idioms (Molé 2008). Even when the consequences of a neoliberal marketplace cannot be felt 'on the skin' (ibid.), they can have negative consequences on disabled people. For instance, Friedner has shown how the promotion of the employment of deaf people in certain sectors of the Indian economy has been predicated upon their immobility, i.e. their tendency stay in a job for a long period of time, or on other characteristics that are stereotypically attributed to them (2013, 2014, 2015). This has impacted their ability to promote themselves freely in the labour market and affected their career development (ibid.). Just as the word 'livelihood' contains the word 'live', our livelihoods, i.e. the process through which we obtain our means of subsistence, affects how we live our lives. If chances of professional ascent are

curtailed, as they are in the case of the 'silent brewmasters' (2013), of the multilevel marketing workers (2014) and of the business process outsourcing employees (2015) described by Friedner, we can expect their life and health, as well as income, to be affected. This is an incomplete selection of publications that suffices to give an idea of the breath of the literature on the intersection between work and ill health.

In some instances, however, medical anthropology has recognised the solace brought by work to people with a disability or chronic illness. For instance, Mary-Jo DelVecchio Good has described work as a 'haven from pain' for two women affected by chronic pain (1992). Moreover, various projects involving people marginalised because of their medical condition have demonstrated the therapeutic power of work. Without the remits of anthropology, the literature on the different programmes through which disabled people can get into work is rich and diverse (see Becker, Lynde & Swanson 2008, Burns & Catty 2008, Crowther et al. 2001, Drake et al. 1994, Gilbert et al. 2013, Schneider 2008, Wehman et al. 2013), as is the literature on how people with different disabilities and pathologies, notably mental illness, can benefit from employment (see for instance Arns & Linney 1993, Fifield, Reisine & Grady 1991 and Drake & Bond 2008). A good example of an organisation aimed at providing work to people who are usually disadvantaged in the job market is Vita Needle, located in Massachusetts, United States. It is described in *Retirement on the Line: Age, Work, and Value in an American Factory* by Caitrin Lynch, who focuses on the benefits of being employed for older people (2012, see also Gershon 2015:164–178). In providing its workforce not only with a job, but with a purpose in (later) life, it is similar to Spring.

A notable example of a project aimed at using work in order to improve the professional and social chances of disadvantaged people, in this case people with serious mental illness, is the Fountain House in New York City. Various 'clubhouses' were modelled on it (McKay et al. 2018), and the original Fountain House is still in existence.[15] After deinstitutionalization, people with mental illnesses in the United

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[15] In this paragraph, I speak of it in the past because I refer to how it was shaped by John Henderson Beard in the 1950s, but many of the changes he introduced are part of the ethos of the organisation today.

States were left isolated (Doyle A., Lanoil J. & Dudek 2013:XVII), lacking formal social support (ibid.) and struggling to obtain and retain employment (ibid.). In sum, although they were in society, they were not truly part of society (ibid:XV). The Fountain House, which had been founded in 1948, was reformed by John H. Beard in the 1950s. In order to solve these issues, he leveraged the power of work, which, in his opinion, 'reflected a more meaningful experience of life than, say, a baseball game' (ibid:30). He understood that employment could satisfy people's 'need to be needed' (ibid:50–51). Since this need is universal, the Fountain House model is exportable to other cultural contexts (ibid:XIX). In the original Fountain House, staff members were not numerous enough to run the institution. Therefore patients, who were called 'members,' had to work alongside them (ibid:51) and, as they could choose when and how to work, they worked in a truly collaborative manner (ibid:33). The challenges posed by mental illness are different from those posed by a sensory loss such as visual impairment. Nevertheless, in the thesis I draw on literature on people with mental illness within and without the remit of anthropology whenever it informs my discussion on narrative or professional integration. For instance, in regard to the latter topic, in chapter 4 I analyse Spring's role in the lives of its workers by comparing it to the Fountain House model, and argue that such role could be better developed by applying more of the Fountain house tenets to Spring.

1.8.b Other Facets of 'Work'

Disability activist Sunny Taylor has argued for her right not to work — and to devote herself, guiltlessly, to her passion: painting. She claims that she, as well as other disabled people, 'will never be good workers in the capitalist sense' (2004:39), and contends that people should not be judged on the basis of their economic productivity (ibid:40). This problematises the above-described nexus between disability and employability by adding the perspective of those who believe to be valuable members of society in spite of not being in employment. Moreover, the literature shows that what counts as work is socially determined (Grint 1998:6, 10–11), and should not be equated with paid work too hastily. Indeed, people can continue to work even when formally unemployed (ibid:37), or can still define

themselves as workers when out of work (Perelman 2007:10). What counts and does not count as work is also a matter of contention: the restriction of the term 'work' to remunerated tasks has been criticised by scholars and activists advocating a fairer recognition of the effort put into various life activities by marginalised social actors. Formulating a bounded definition of such life activities would not do justice to their multiplicity, and harm the attempt to give each of them their fair recognition. Anthropologist Sara Bergstresser appropriately argued that the 'never-ending management of an illness is physical and emotional work yet not productive in the economic sense' (2006:15). This is the most basic facet of non-professional 'work' carried out by my participants that I will discuss in the thesis. There are, however, many more nuances and manifestations of non-professional 'work' that I will mention throughout the text, such as the effort to define the boundaries between oneself and other visually impaired people (chapter 2), the sociality of the workplace (chapter 3 and 4) and, most importantly, the various types of 'narrative work' that give structure and meaning to people's lives after sight loss.

Among the many publications on different types of 'work,' I will start my discussion with the unpaid work carried out by women in heterosexual relationships as presented by sociologist Arlie Hochschild (Hochschild & Machung 2012, see also Newell 2000), who unpacks the complexities of female partners' unpaid chores (as well as their struggles, negotiations, and complacency in the name of peaceful living). Whenever I witnessed the preparations that my visually impaired interlocutors had to make before joining a sports event, going to work, or taking care of their homes, the term Hochschild coined, 'the second shift' (Hochschild & Machung 2012), was vivid in my mind. It also seemed to encompass really well the work that workers at Spring did at home before and after a day at the factory, a work that was, needless to say, unpaid (see portrait of Jim, chapter 3). Hochschild was also the first to use the term 'emotional labour' to refer to the emotional adjustments that people in the workplace make in order to present the demeanour that elicits just the clients' right state of mind desired by the company (2003:6–7). The two extremes she presented were flight attendants, who have to use friendliness to enhance the status of their customers and therefore sales, and bill collectors, who have to leverage their anger and mistrust to humiliate and intimidate customers (ibid:16). The emotional efforts made by my participants are more appropriately named 'emotion work' since,

in Hochschild's definition, 'emotional labour' means 'the management of feeling to create a publicly observable facial and bodily display' that has 'exchange value,' whereas 'emotion work' refers to 'these same acts done in a private context where they have use value' (ibid:7). Among the different types of emotion work I encountered among my interlocutors was the one carried out whenever they had to negotiate how to accept help from sighted people: accepting too eagerly would make them passive and complacent; refusing too abruptly would offend the sighted party, and perhaps even lower the likelihood that they would offer help to a visually impaired person in the future.

In addition to the examples presented above, non-remunerated 'work' comes in various shapes, such as physical, emotional, social, intellectual and artistic. For instance, in a medical context anthropologists have studied 'illness identity work' (Estroff 1985) and, in a broader context, unwaged labour (e.g. Muehlebach 2011 on voluntarism). Crucially, some activities that are not normally expected to be remunerated have been analysed by anthropologists under the lens of work. For example, Korean Chinese's waiting for their emigrated partners' remittances and for a future life together has been described as 'unwaged affective work' (Kwon 2015:480). Waiting can also be a component of 'asylum-seeking work,' also called 'making-paper' work, i.e. the effort asylum seekers put into their applications, often at the expense of spending time in waged work (Shrestha 2019). In a global health context, paid or unpaid work, in particular women's work (Maes et al. 2015), has been at the centre of various discussions. Historically, some types of work have moved from the private sphere of informal and unpaid care to the professional domain of paid care (Eden 2017). At the same time, past ideologies continue to influence the integration of certain categories of people into the labour market. For instance, in some ethnographic contexts women consider 'full-time mothering' as more noble than sharing one's time between employment and childcare (Stockey-Bridge 2015:92), a choice which is, incidentally, not labelled as 'part-time mothering' (ibid:93). In some instances, one facet of work has become more prominent than the other, as is the case of the business side of farming as opposed to its agrarian side (Ofstehage 2016:456). This has made office work more typical of the life of a farmer than work on a tractor (ibid.). In other cases, workers defend their right to bestow a smaller or a greater share of their human side to the people they care for as

professionals, without letting this human side be commercialised by interfering employers (Paerregaard 2012). Social actors may also ennoble a stigmatised type of work by giving it a more official patina: the beggars described by Clara Devlieger tried to legitimise their position by issuing certificates to their donors (2018a). Moreover, anthropologists have pointed out that international organisations' discourses highlighting the heroic and altruistic nature of a job may eclipse workers' own moral economy and their struggle for fair remuneration and humane working conditions (Closser 2015, see also Glaser 2017). This overview of the anthropological literature of what counts as work is, inevitably, incomplete, but it suffices to shed light on how diverse the activities that count as work are. It also reveals how the issue of defining work intersects with topics such as migration, development and gender.[16] I propose to address the intersection of work and narrative: my own thesis contributes to this highly thought-provoking field of anthropological enquiry by showing what types of work, both professional (work) and non-professional ('work'), gave my informants the engagement and dignity they needed in order to reframe their lives therapeutically.

I now introduce the story of Dietlinde, whose life features many issues common to my participants: the personal, professional and social repercussions of sight loss, the restructuring of her life in multiple domains, and the appreciation for what she can still enjoy.

1.9 'The Best Thing after Sliced Bread': Adaptations to Domesticity and Sociality in the Life of Dietlinde

The domestic domain is considered to be highly private in Britain, where people socialise mostly in the public domain. But what happens when an anthropologist needs to be socialised into the daily life of a person who lost most of her sight? Dietlinde opened the door of her home to show me how life goes on, day after day, meal after meal, even after a progressive and late-onset sensory loss. Her home is a nest of comfort jarring with the dramatic nature of her story of sight loss, which she

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[16] For the theoretical frameworks developed within sociology to characterise care work, see England 2005.

recounted while we were sitting in her lounge. Her home is where we had most of our interviews and interactions, but it is also a space that spoke for itself through the sedimentation of numerous pieces of adaptive equipment acquired over the years. Better financial circumstances may allow some visually impaired people to adapt to their impairment better, but they may be a blunt sword when fighting against the more severe stages of sight loss. What remains of Dietlinde's more secure socio-economic position is perhaps not her technological equipment, but her capacity to envisage herself beyond her home, in the company of her equally cultured friends, by the side of a grand piano or sitting at a fashionable restaurant.

> *The movement classes are absolutely wonderful: we are in a professional studio, being taught ballet movements by ex-principle dancers, while a professional pianist plays on the grand piano for us, wonderful. And, after audio-described tours at the [names of important galleries in town], we sit in the most beautiful rooms. It makes me feel inclusive [sic], pursuing all my hobbies even though I am blind now. Donchester has so much to offer. I have discovered only one tenth of what is available.*

Dietlinde is in her 70s and lives in a middle-class semi-detached home in the suburbs with her husband. She has spent more time in Britain than in her home country in central Europe, where she was born. She responded to the call for participants I sent out through the disability officer at a major museum during the early stages of my research. In fact, she is very 'research-conscious': she has helped various researchers before me, and is familiar with the principle of informed-consent. She even says she regrets rambling too much during our recorded interviews, as she is aware of the long time it takes to transcribe them.

Most of those interviews, as well as our informal conversations, are pervaded by her appreciation of the plethora of leisure opportunities available to visually impaired people in Donchester. 'You can't be bored in Donchester,' she tells me. Besides ballet classes and touch tours at museums and galleries, Dietlinde has joined walking groups and book clubs. She is also a regular at audio-described theatre performances, and she calls audio-description 'the best thing after sliced bread.' After she completely lost her sight, she took to radio 'like a duck to water,' but the

smooth transition conveyed by this metaphor belies the horror she felt when she lost her sight 'one minute to the next.' This expression recurs in Dietlinde's speech at least as frequently as her words of gratitude towards the innumerable cultural programmes aimed at people with sight loss.

'I never had full sight, to be honest,' she tells me when she starts recounting the story of her life. Honesty is an incongruent concept to use in the context of a medical history, but one that is more understandable in the light of the embarrassment she felt for being visually impaired before her diagnosis, and in light of the guilt she experienced after her diagnosis, when she blamed herself for not having had her eyesight checked more promptly. 'It didn't worry me,' she tells me as she describes the tell-tale signs of sight loss that she did not heed.

> *In 1973, when I tried to do a driver's licence, I found out that I could never drive at night. I used to meet my friend at a place… I never knew what it was called, because I could not read the inscription. One day my friend said: 'Let's meet at [name of the place].' I asked: 'What do you mean?' 'Where we always meet! You didn't know the name?' 'No, I can't see it!' I was in my late teens/early twenties then. I should have gone then to the optician. I took my health for granted; I did not earn a lot of money, and the optician was expensive, but still I should have gone. I keep thinking back about that. I only went when I was 25, but even then I was only given glasses, which became stronger and stronger with time. People used to say: 'You are clumsy,' so I thought 'I'm clumsy.' I blamed myself for my visual impairment, and I did not know much about visual impairment then, I had never had anything to do with blind people. Only in England did I go for a proper sight test, I think in 1989. I went to the optician, and he advised me to ask my GP to refer me to the eye hospital. When I went there, I was diagnosed with [name of condition]. I felt so relieved.'*

The physician explained to Dietlinde what was happening to her eyes, and that her disease was progressive. This was a turning point, as she started to come to terms with the fact that the disease could not be stopped.

I went home and said 'You know, [husband's name], I've got a condition.' It was like a revelation. I felt light weighted: 'It's not just my stupidity. There's a reason for it.' I was glad to have a name for it: even if I bump into something, now there's an explanation.

Curiously, though, she still felt she had no visual impairment, as she struggled the most only at night, when many people do not see very well anyway. But her sight loss got worse and worse, and in '98 it was such that she actually had to give up driving, and she was registered as visually impaired.

Once I got registered as low vision, it took 1, 2, 3 years till everything was in place. I had mobility training, which was provided by the council and was good. We also had to make adjustments in the house, to make it safer for myself. We installed four lights in both front rooms, and spotlights in the bedroom, at my desk. We also put lights under the kitchen cabinets. I bought a kettle that lights up, although I can't see that anymore, and we gave up all carpets, so that it is easier to clean the floor.

Dietlinde seemed to have found some balance in her life. However, calamity struck:

It was May 2003. From one minute to the next, I couldn't read. I was in [home country] to visit my Mum on mother's day. I wanted to check my messages. First, I thought there was a problem with the light: 'Did you switch off the light?' 'No, what do you mean?' she replied. When I came back to England I realised I couldn't read anything. Now, even a huge poster I can't read it, I can't read it. It can be as large as the whole world, and I can't see the letters. I was horrified.

Losing her capacity to read was a shock for Dietlinde.

I started reading at an early age. I was always an avid reader, I read non-stop. I was reading news, basic stuff. At that time we had an oven, and it was my job to put paper, coal into it, so when my mum came home she could cook. But I had to read all the newspaper first before burning it.

Dietlinde literary taste grew more sophisticated after she met her husband, and in 1997 she started studying for a degree in literature, as it was the last year of free university education in England. Shortly after finishing her degree, she experienced the sudden sight loss described above. That was when her husband started looking after all their administrative affairs, and Dietlinde said that she does not know how she would have coped if she had been on her own. Moreover, she was referred to an RNIB training centre, where she completed a one-year graduate scheme. The position was fully paid, and gave her the opportunity to learn the use of a screen reader and other skills while working as an administrative assistant at the department of education and employment. She thoroughly enjoyed the position, which she found creative, as it entailed booking train tickets, flights and venues, as well as transcribing information and ordering stationery. She recognises that, among her fellow trainees, those who had been blind from birth performed better, especially if they could read and write Braille. She never succeeded in learning this script, which is not unusual for an older person, as it requires great tactile sensitivity. However, she did learn some Moon script, a tactile system of raised shapes suitable for people of all ages, although not of practical use in a clerical environment. In regard to her experience at the RNIB training centre, Dietlinde acknowledges her own resilience in being able to complete a programme that was so hard and stressful that many participants, younger than her, abandoned it in spite of the salary being paid.

After graduating from the programme, in 2004, she tried to find a job. The task proved 'impossible.' She went to many interviews but secured no position. She attributed this to her age as much as to her visual impairment, as she was by now 'over the desirable working age,' and felt 'humiliated.' She had held jobs before she completely lost her sight, including one at a department store and one at a bakery, but even her previous experience made no difference. Her job search was particularly arduous when she competed against candidates who were more qualified for the positions than her. She therefore started volunteering for the RNIB 'talk and support' team, until her sight deteriorated so much that that she could no longer see the items she needed to describe, and felt useless in her role. Various experiences during her job search made her realise that employers were 'ignorant,'

over-concerned with health and safety regulations, and had a low awareness of what blind people can do. She recalls being left alone in a booth with a computer without speech software during an assessment test. She explains: 'I had to enlarge, letter by letter, but the more you maximise, the less you see.' Her sight was so poor that she could only display one word on the whole screen, and at that time she had not been fully trained to adjust her computer. Still, she managed to complete the task. At the end, the recruiter wondered why she had not asked for help, without considering that Dietlinde had been left alone in an office she was not familiar with.

Dietlinde is known for her determination — she will never let me carry her shopping bags, no matter how hard I try. The effort she was not given the opportunity to put into work, she puts into cultural and social pursuits: 'I say to myself: if I don't work, there are so many opportunities. That's why I keep myself busy.' As we sit in her sitting room, she tells me what she did yesterday:

> *I cleaned, I cooked, I did my shopping, and then I went to a museum in central Donchester. I was very happy about this outing, which was an event for VIPs [visually impaired people]. I went with another VIP lady I know, and then we treated ourselves and went to a good restaurant.*

Dietlinde likes pampering, and a glass of wine and chocolates are often welcome accompaniments to an audio book, an audio-described film, or any other leisure activity. She often takes part in such activities with friends or acquaintances, and she is quite well-known in the VI community. Her week is not short of opportunities for self-indulgence, but is at the same time quite structured.

> *On Monday morning, my carer comes, during the day I iron, and in the evening I go to the visually impaired ballet class. On Tuesday I used to go to concerts, while on Wednesday I go either to a gym in the city centre or for a walk, or, sometimes, to the aerobics class at my local church. On Thursdays my carer comes again, and in the evening I may go to a screening of the opera at the local cinema. On Friday I do not plan anything, I keep it for myself, while I spend weekends with my husband.*

She feels quite guilty in regard to not being out at work like everybody else, and not having had a full working career. She feels particularly guilty vis-à-vis her husband:

> *When he leaves for work in the morning, I think: 'Goodness, isn't that unfair. If I was still working, he would not have to be out working now, we would have enough to live on.' I retired in 2004; I should really have carried on for another four years. I make sure when he comes home he doesn't have to do anything.*

That is why, when it comes to the 'smooth running of the house,' Dietlinde has it 'down to a T.' To her, having a routine is strictly linked to independence, which in turn is 'the most important thing': 'When you are blind, you really need to have a kind of a plan. The routine tells me where I am, so to speak, the routine gives me security.' One of the things I helped Dietlinde with when I visited her home during my fieldwork was to write different activities on her calendar, on which her husband reads to her every morning what she has to do. It is interesting to notice that she keeps it near her canes, just inside the main door.

Being able to walk around on her own is also something that makes her feel independent. When she became sight impaired, she tells me with a hint of sadness, some of her friends deserted her, and even now it is not easy to find company when she goes for a walk in her local area. Therefore, she has devised and memorized a route that she can walk on her own, if she wishes to take some exercise. Also, she is so confident in walking around her neighbourhood, where she has lived since the mid 1980s, that she often strides ahead of me, and I have to quicken my pace to keep up with her. When we visit the local shops, she walks so vigorously that she almost bumps into people. 'I know where I'm going, I know all the routes here within three miles, all the way around. But in the dark, forget it. I can be in my own road and I'm lost.' Walking a distance that could be covered in five minutes may take her half an hour. Even when on her own road, where she can recognize her neighbours by their voices, at night if she hears steps behind her she worries, and she gets stressed. 'I'm so glad that I still have peripheral vision because, if I didn't have it, I would probably stay at home.'

To Dietlinde, one of the greatest things is being able to use the public transport network at no cost, courtesy of her disability pass. Public transport is indeed essential to all the activities mentioned above, in that it enables 'the spatial relations' that 'are the condition and the symbol of human relations' (Simmel in Wolff 1950:402). Dietlinde particularly treasures the 'walking taxi,' the pick-up service offered by some volunteers who take visually impaired people from the nearest underground station to the venue. Dietlinde has even tried using Navigon, a navigation app she downloaded to her iPhone.[17] Her iPhone is indeed full of unused apps she intends to delete, which are also an index of how keen she is on using this device. 'The best invention in the last ten years is the iPhone. I have had mine since 2012, and I still have not mastered it.' When she bought it, she took one-to-one lessons, but she also learnt something from two friends who bought it at the same time as her. In response to the fact that some visually impaired people struggle to learn how to use this and other devices, she says: 'I understand people are frustrated. But if you have the time, make time.' She points out that her congenitally blind friends learnt to use the iPhone in only three months. Although it took her much longer, she is now a champion of this particular product, like many other blind participants I spoke to: 'I keep learning to use my iPhone. Once I have learnt more, I'll give up everything else. I'd also love to give up the computer, because the less you have, the less problems you have.'

For the time being, however, Dietlinde's home is replete with devices, which she acquired over the years, that help her cope with her visual impairment. Her polymedia (Madianou & Miller 2013) is just as rich as her social network: at the moment, she uses her computer, not her iPhone, to send emails, and she hired an IT tutor to teach her Outlook. She still keeps her little Nokia mobile phone as a 'security blanket,' as it is quicker to send text messages with it. Besides these IT devices, she still keeps a magnifier, on loan from a sight loss charity, although her sight has deteriorated so much that she cannot use it. She also has on permanent loan a radio that she could not locate. She described it to me, and told me where she thought it was. I found a coffee machine there instead, which she recognised as soon as she

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[17] Like all Apple devices, the iPhone has inbuilt accessibility functions, such as voice-over and screen magnification.

touched it. When I eventually found the radio, we tested it and it worked. It had big buttons, and could be used as a CD and cassette-player, reader of audio-book discs, as well as radio. Dietlinde also has the RNIB's PenFriend, an audio labeller with which we tagged the tickets for the theatre shows she was going to attend during the next few months. First, I stuck a PenFriend label on each ticket. Then I took the labelled tickets one by one and scanned them with the PenFriend device, which is slightly larger than the size of a pen, and recorded my voice reading the name and date of the specific event. In order for Dietlinde to locate the right ticket, she just had to scan each label and hear the details of that particular performance being played back by the device.

In principle, the kitchen is also a place where many devices that are designed for people with sight loss can be found. However, Dietlinde laments the fact that many talking appliances cost a multiple of the normal ones. For instance, the price of a talking microwave is 250 pounds, versus the 30 pounds of a normal model. Some talking appliances do not exist at all: dishwashers, cookers or washing machines. Dietlinde uses a talking scale, and we once went shopping together for a (non-talking) white coffee machine, as she wanted its colour to contrast against the darkness of the drink.

Technology allows Dietlinde to do many of the things she wants, but it can also be highly temperamental. Alexa, which she has in her sitting room, won't always respond as she expects, and the computer can go silent:

> *My computer was not speaking to me, but I knew it was on because I could see the light. I had to answer emails, write a report, and I could not do it. I was very bored not being able to get on with it, so I went for a walk, because there was nothing else I could do. I needed a sighted person to look at it, so I waited for my husband to come home. But, in the meantime, in order to get rid of my frustration, I just went for a walk.*

Dietlinde brought up this incident in response to a question I asked her about boredom. In her words, however, it is frustration that can be sensed, but also relief. Some of my other participants have commented on just wanting to get out of the

house sometimes and go for a walk in the park or along the beach, but being kept home by their disability. Dietlinde has carved for herself a niche of spontaneity, whereby she can go for a stroll in her immediate neighbourhood, and she has done so through determination and practice. She has also put a lot of work into reshaping her identity, taking into account that, while she could still read large print, she did not consider herself as visually impaired. It was only after the 'horror' of her sudden sight loss that she started meeting other visually impaired people by joining various charities. Over a decade on, her gratitude is palpable: 'We are so lucky in this country. The availability of support here is fantastic. We don't have to stay in our houses, there is so much to do.' At the same time, she wants to point out that she does not mingle with other visually impaired people with the purpose of crying on each other's shoulders: 'A problem shared is a problem doubled. That's true. When you get together, don't talk about your problems.' More importantly, she is conscious of the necessity to be independent: 'Most of the time it is good to be totally self-reliant, because everyone has got their own life, they all have busy lives.'

Listening to Dietlinde talk about her daily life experiences, one can perceive her fluctuating between her steadfast belief in independence, and dependence. She adheres to the former by asserting 'I don't want to be dependent on other people, that would really destroy me;' she conforms to the latter by praising the assistants on public transport, who are 'worth their weight in gold.' Again, she says: 'When I'm out and about by myself I rely on strangers. I can't see the shops, but when I think I am near Boots, for example, I start asking: "Am I near Boots?" No one has ever complained. It is wonderful.' She is wary of such dependence, though, lest she falls prey to thoughtless passers-by:

> *I was near my home once, when a lady grabbed me by the arm without warning, without saying 'Hello, I am so and so.' That's criminal. She walked with me for a while, then she lost interest and left me. She just said: 'Three or four more steps and you are there.' Thank goodness it doesn't happen that often, and I would recognise her voice if I hear her again, so I will not take any advice from her.*

That is why, according to Dietlinde, education is a top priority when it comes to raising awareness of any disability. She refers to the need to educate those strangers grabbing her by the arm without consent, but also to the importance of educating all people in regard to eye health. The thought lingers on in her mind that, had she seen an optician earlier, she could have undergone training earlier, and adapted to her disability more quickly and efficiently. Dietlinde's adaptation did not happen 'from one minute to the next,' but her determination has pushed her so far beyond her physical and personal boundaries that, as she steps out of her front door, she inspires whoever meets her, whether it is at an audio-described performance, or at her local grocery shop.

Chapter 2. 'Every Visually Impaired Person is Different': The Visually Impaired Community in Donchester

2.1 Introduction

After outlining the essential notions on the semantic, medical, and social aspects of sight loss (chapter 1), I would like to turn my attention to the visually impaired community in Donchester. To what degree is it fair to speak of a 'community'? In this chapter I point out the paradox whereby all of my participants claimed to be different from each other, but at the same time appreciated the sense of mutual understanding present among them. I illustrate the benefits they derived from being part of this community by describing the sight loss charity I call 'Sunshine' and one of its users, Sam. I place this chapter at the beginning of the thesis because, for most visually impaired people I spoke to, whether to associate with people with the same sensory impairment or not was one of the first decisions they had to face when confronting their sight loss. Taking this decision entailed beginning to narratively incorporate their disability, whether congenital or adventitious, into their lives. Like all forms of emplotment, though, this process was both fulfilling and precarious: navigating the space between community and independence was a type of 'work' that visually impaired people had to carry out throughout their lives.[18] Because this 'work' was what brought the visually impaired person, in particular if adventitiously visually impaired, out of a phase of dejection and denial, at this stage narrative was not fully formed. In fact, it could be considered as a chaos narrative (Frank 1995:115–136). Therefore, narrative will surface only surreptitiously in this chapter, whereas it will be featured more explicitly from chapter 4 onwards.

Before I delve into a discussion of the visually impaired community in Donchester, I would like to make an important proviso. This thesis focusses on visual impairment, but there are other factors at play in the lives of my participants. A discussion of the socio-economic disparities that cut across British society are beyond the scope of

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[18] Cfr Kavedžija 2015b:143–144, 2018 and 2019b:122–129 on Japanese elderly people's conundrum between intimacy and independence.

the present work, and yet they are structural factors that profoundly affect the people whom I present in this thesis. When I was starting my research and trying to learn as much as possible about the daily lives of a wide range of visually impaired people, I heard the phrase 'every visually impaired person is different' many times. My interlocutors referred mostly to differences in personality, taste, sight condition and adaptation to sight loss. The additional important difference that was not overtly articulated but that, as I came to realise, impinged upon my participants significantly was the one in social class and financial situation, as well as in ethnic background. Visual impairment may jeopardise a person's financial circumstances not only because it threatens their employability, but also because it gives rise to increased expenditure of money. For instance, special equipment would need to be bought and minicabs to be booked. Moreover, living with sight loss may make house-sharing more difficult, thus leading some people to live alone, which, in a city like Donchester, is much more costly. Visually impaired people face these challenges with more or less anxiety depending on their socio-economic status. 'My bugbear is having to pay a premium because you are a disabled person,'[19] told me Laila, an underemployed woman of colour. In the present work I limit myself to visual impairment and do not delve into intersectionality, but it is important to remember that social phenomena, including social inequality, are determined by multiple interacting factors (Hill Collins & Bilge 2016:2). Also, although I lay emphasis on the initiative and hard 'work' that my informants put into reframing their lives in the face of sight loss, it is fair to reflect on whether, for instance, William (chapter 5) would ever have become a storyteller if his parents had been factory workers, rather than literature teachers, and if he had not had a degree from a prestigious university. Also, what could Jim (chapter 3) have become professionally if he had remained in education after the age of 15? The fact that they are both happily content with their personal and professional lives should not obscure these issues. If it is hard work to be visually impaired, being visually impaired, poor, and of a different ethnic background can be 'grim work' (Mattingly 2010:4).

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[19] For a systematised review of the literature on the direct costs associated with living with a disability at the individual or household level, see Mitra et al., which indicates that individuals with disability have to face 'sizeable extra costs' (2017:480).

2.2 The 'Work' of Joining the Visually Impaired Community

As an anthropologist wishing to define the scope of my enquiry, I was aware of the difficulties of forming a pool of research participants when studying a population that does not constitute a bounded community. Differences in socio-economic background, level of education, ethnicity, age and gender, not to mention their scattered geographical distribution, made visually impaired people in Donchester seem an atomised series of individuals. The sense of unfathomableness of the visually impaired community I felt at the beginning of my research was exacerbated by the fact that, paradoxically, many participants told me: 'I am not by any means representative of blind people.' Statements of this sort formed the first pattern that emerged from my initial conversations with people with sight loss. I therefore regarded it as worthy of investigation, and started considering it in the light of the medical anthropology literature on people who find themselves put 'in the same basket' because they have the same medical condition, but who are actually in strikingly different life situations (see Gatter 1995:1526).[20] This sense of isolation from mainstream society on the one hand and of forced identification with the visually impaired community on the other was shared by my own participants. One of them put the matter into a few cogent sentences: 'People don't talk about 'the sighted': they talk about 'sighted people'… That idea of the blind, amorphous group. The idea that blind people would automatically have things in common and therefore it's good for blind people to go and socialize together.' Another one said: 'I don't find my blindness gives me anything in common. They [visually impaired people] are an alien species to me.' If 'everyone is different' was the refrain of visually impaired people, it was also one of the core principles of various charities with which I came in contact as part of my interest in sight loss. This individual attention, in turn, was much appreciated by visually impaired people, since it meant that their needs, as well as their likes and dislikes, were taken into consideration when they took part in group activities. On these occasions they were taken care of as people, without letting their disability loom large.

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[20] See also Chevigny & Braverman, who observe that blindness strikes blindly (1950:25), but that society insists that blind people constitute a group (ibid:36).

If my participants felt it was unfair to be put into the homogenous category of 'visually impaired, one type of classification that they did accept was the one between congenital and adventitious sight loss. Regardless of which category they fell into, visually impaired people believed that those who had been blind or partially sighted from birth, or from a very early age, were clearly advantaged in performing various daily tasks. Similarly, some born visually impaired or early visually impaired people attributed their better adjustment to their sight loss to having attended mainstream, as opposed to specialist, schools. On the other hand, it was thought that those who had previously had eyesight found it easier to just 'fill-in' some information missing from their visual mental picture through the other senses. At the same time, one of my participants warned me against conflating congenital sight loss with confidence: in her opinion, the family played a big role in developing this skill through upbringing.

In carrying out fieldwork and interviews with visually impaired people I found that, regardless of how long they had been without sight or with partial sight, they all had to restructure their sense of self around sight loss. Their openness to self-transformation was usually proportional to their willingness to approach other visually impaired people. Given that they may be the only sight impaired members of their family and that in Donchester socialization in the non-professional domain revolves around interest groups, befriending other people with sight loss often happened through joining specific visually impaired groups or organisations. In this chapter, I use the term 'group' to refer to this type of social circles, and 'community' to refer to both the broader network of people with sight loss in Donchester, and the visually impaired community at large. Entering the VI community often entailed becoming part of VI groups, for instance that of the charitable organisation Sunshine, described below. The process of becoming part of the visually impaired community was harder for people with adventitious visual impairment because they had acquired the stigma (Goffman 1990[1963]:13-15) of disability later in life. Moreover, being able bodied was still fresh in their minds, and their transition to a disabled status was felt more acutely (see Murphy 1990). As a consequence of all this, the 'work' of coming to terms with having become visually impaired was particularly intense in the period shortly following loss of sight. Nevertheless, people whose sight had been impaired from birth also had to revisit their life narratives whenever sight loss became an issue because of its deterioration or, more frequently, because of the barriers it

started to pose in the social sphere. In sum, emplotment was equally present among adventitiously and congenitally visually impaired people. In the introduction, I presented a view of narrative that does not strictly distinguish between life as lived and life as narrated. In this case, emplotting oneself as visually impaired through frequenting groups of people with sight loss[21] happened 'in action,' and was only rationalised through narrative in retrospect.

In this chapter, I argue that for my participants negotiating their belonging to the visually impaired community was a form of 'work,' as it required a lot of effort. The main difficulty lay in the fact that judging how close or how far they should be from this community entailed reconfiguring who they were as a person. Going to a crafts class tailored for people with sight loss, for instance, meant labelling oneself as 'person with sight loss.' In fact, it is hard to disentangle the belonging to a community of visually impaired individuals with a face and a name from the belonging to the broader 'visually impaired category.' Indeed, the boundaries between a concrete community of visually impaired people and an 'imagined' community' (Anderson 1983) comprising all people with sight loss are permeable. Managing the distance between the VI self and VI others involved re-crafting one's personal life narrative, and that is why the topic of community merits special attention in a thesis focussing on work and narrative.

The narrative 'work' of joining the visually impaired community, and through it of adopting the idea of oneself as visually impaired, was initially hindered by denial and rejection. These sentiments were especially common among adventitiously visually impaired people such as Dietlinde, Andy and William. The trajectory leading towards acceptance was far from linear, and mimicked that of the broader process leading to therapeutic emplotment described in chapter 5: after a period of shock caused by the advent of sight loss, the individual found a new, though precarious, equilibrium within oneself and in relation to others. Analysing the attainment of this new balance and the engagement with the visually impaired community, it is hard to distinguish which caused the other. Feeling confident as a visually impaired person may be conducive

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[21] See below on the visually impaired community being led by sighted people, which suggests that some of these groups may be, from the point of view of the organisation, *for*, as well as *of*, people with sight loss.

to frequenting other people with the same disability. At the same time, something that helped bring about this new balance was the engagement with the visually impaired community. In fact, as my fieldwork progressed, I came to learn where at least part of such an apparently amorphous mass of people coalesced. I discovered that there was such a thing as a visually impaired community in Donchester, i.e. a subgroup of people suffering from sight loss who frequented events tailored for people with this particular sensory loss, and forged acquaintances and friendships with other blind or partially sighted people. In some instances, although this is beyond the scope of my research, groups may form on the basis of additional shared characteristics besides visual impairment, such as ethnicity (Priestley 1995). Moreover, communities may form online, although the lack of IT literacy of a section of my participants, notably workers at Spring, discouraged me from pursuing this strand of research further. The feeling of common understanding that users of sight loss groups gained is well illustrated in the fieldwork data I collected at Sunshine. In the following section I describe the therapeutic role that this charitable organisation played in the lives of people with sight loss, in particular adventitious sight loss, while later in the chapter I will present the more contested boundary between dependence and independence.

2.3 Sunshine

Sunshine's main purpose, according to the organiser of the courses as part of which I volunteered, is to 'relieve isolation' and to encourage participants, particularly those who have not yet adapted to or come to terms with sight loss, to be socially active. The courses are tailored to people aged between their 30s and their 60s who are 'sitting at home' because of their disability. Among the different activities organised by Sunshine are IT, arts, yoga and cooking classes offered at a small number of community centres in different parts of Donchester. I regularly volunteered at two of their locations. Users can be referred by a friend, a family member, a charitable organisation, or their local authority sensory team, but they can also apply to attend a course on their own initiative. The number of users attending each class can range from one to around eight, depending on people's other engagements (hospital appointments, holidays) or circumstances (health, weather, and light conditions).

From time to time users bring along one or two friends or family members. Tutors are particularly accomplished at making everyone feel welcome and at accommodating to individual likes and dislikes, as well as needs. Staff members of the organisation and a volunteer are available to serve tea and coffee, help people navigate the space and provide support during the class. The atmosphere is quite relaxed and convivial and, during classes that do not require total concentration, people chat about current affairs or about various topics related to their lives. They may also talk openly about their sight loss, its onset and its consequences. The composition of the classes is quite diverse ethnically and generationally, with some attendees being young, some middle-aged, and some elderly. Most users come from within the catchment area of the particular centre. Although the two community centres I attended are located in areas of the city that are quite apart from a socio-economic perspective, I did not notice any particular socio-economic differences between the two groups. In fact, each group is equally diverse and brings around the same table people who would not otherwise have met. Some users come either for the morning or for the afternoon class, whereas others stay for both, and eat a take-away lunch or a sandwich together, alongside the volunteer and the employees of the organisation that are present. It is not rare to see the employees being consulted about problems unrelated to the courses. They either direct users to organisations that provide advice on the particular issue, such as housing, or directly provide help and advice regarding problems they are sufficiently informed to comment on, such as transport. In this regard, the charity takes care of the booking of the free transport service, which is provided by the local council, for users who attend its classes. In the following section I present the 'portrait' of Sam, a user of Sunshine, through which I introduce two issues that will be discussed later in the chapter, and that are sometimes at variance with each other: the benefits of taking part in the activities organised by a sight loss charity and the struggle, or the 'work,' to maintain one's independence.

2.4 'Like Life before We Lost Our Sight': Solace and Resilience for Sam, Elderly Sunshine User

The pseudonyms I chose to help conceal the identities of my individual and institutional participants bear no relation to their personalities or characteristics. Sunshine, however, is an exception: just as sunshine is notoriously rare in England, so is the accommodation that Sunshine offers to its users rare in mainstream society. Defying physical hazards, as well as the social indifference that produces them, Sam and his brother regularly go to the community centre where the classes are held. Having become partially sighted in later life, Sam had to face the challenges of adapting to his sensory loss while his physical strength was also declining. Just as, for workers at Spring, producing confectionary products was a pretext for participating in the world of employment, so are classes a pretext for Sunshine users to enjoy the respite that comes from being among understanding individuals. As anthropologists, we are well-positioned to lend a listening ear to people whose stories, for no fault of their own, travel to fewer listeners than they would deserve to. By asking Sam to sit with me during the lunch hour to expand on the topics he touched upon in the informal conversations during the classes, I perhaps offered him a space of heightened attention, an opportunity to share with composure the troubles that dignity and self-respect prevented him to fully disclose in public.

> *I must admit I was worried in the beginning because I had visions of many young people, and I thought: 'Oh God, in our 70s we are gonna be hopeless!' because I've got spinal trouble as well, and my brother obviously had to learn to walk, and I thought: 'Oh, we are gonna not last, because we are not gonna be able to do it,' but the tutor is marvellous, and she does individually help, and understands, and that has also been extremely good.*

Sam is telling me about the apprehension he felt concerning joining the yoga class at Sunshine. He is in his mid-70s and, as the quote suggests, he is burdened by multiple conditions, including the one causing his visual impairment, as well as by his role as primary carer of his elder brother Dave, with whom he lives. I refrain from

coupling visual impairment with burden in this thesis, but Sam's slow rhythm of speech, his sluggish demeanour, as well as his curved posture convey such a strong sense of long-lived tiredness as to make this conflation warranted. By the end of the portrait I hope, however, to have conveyed an image of Sam as a person that is just as proud and resilient as he is burdened.

When he lost his sight seven years ago, Sam knew nothing about Sunshine. It was only three years later, when his brother also became visually impaired, that somehow — he does not remember how — he was put in touch with the charity. The two men started using the befriending services also provided by Sunshine, which sends volunteers to the homes of isolated individuals to converse with them on a regular basis. That is how Sam and Dave learnt about the yoga class and, rather reluctantly, signed up for it. A few months on, they are still attending the yoga class, have started the arts course, which also takes place on a Thursday, and have tried the IT lessons.

> *This day on Thursday we look forward to all week, because fortunately we are lucky we get [name of free public transport service] that brings us here and takes us home, we haven't got to struggle, trying to get… 'Cause this is not very near to where we live and not easy to get to. All right for people that are mobile, but not for us: it would take us…. I did actually go home by bus once. [Realises he has made a mistake] No, not from here. So we get up, we get washed and dressed, eat, have something to eat, and then wait for the doorbell to ring, and we go to be brought, whether it is snowing, or raining, or what, it's like… It's five hours when we haven't got to worry about trying to get somewhere, we are brought here, and like the art… We can't do that at home, we haven't got the room, you know, and obviously it's messy, we've got very limited space, and we thoroughly enjoy that, it's like life before we lost our sight, and […] it brings back to you that yes, you haven't done something like that in all that time that you've lost your sight, and… thoroughly enjoy that.*

The joy that transpires from Sam's words is akin to that we will hear from Andy, who rediscovered his passion for the theatre thanks to audio-described performances (chapter 5). It can also be compared to William's rediscovery of the works of

literature he knew, which laid the foundations for his new job as a storyteller (chapter 5). Creating a connection with what one used to do in their 'life before they lost their sight,' as Sam phrased it, is more than refreshing: it is one of the steps through which visually impaired people emplot their life after sight loss therapeutically (chapter 6). As they try new activities, or do old activities in different ways, their life, restricted by visual impairment in some domains, acquires potential in others. In fact, Sam also told me that the arts classes had spurred him to cultivate the idea of going back to weaving, which he had not done in years. This helps visually impaired people recraft their sense of who they are in a more positive light.

Sam also talks about the benefit of getting together with other disabled people at Sunshine and at other groups for disabled people. Such benefit is twofold. Firstly, such spaces provide staff trained to take care of people with special needs, and a hazard-free environment. At Sunshine, the atmosphere is always restful and caring. Sam contrasts this to the hustle and bustle of Donchester, which he describes in this eloquent passage:

> We are restricted into how far we can go, we obviously haven't been very far in the last, say, four years. Dave can walk to some degree with two sticks, but if we are gonna go… I don't know how many yards he can walk. If we are gonna go… I don't know what the distance is, I've gotta take a fold up-wheelchair, and so that is quite hard, because I'm about nine stone, Dave is about fifteen and a half, and so they are not easy to push along, and actually getting across a road if you are at a traffic light, which is safer, those traffic lights with the numbers on, literally in our main high street the only people who could get along before it goes up '4-3-2-1,' is extremely fit people. People with eyesight problems, luckily you can see the signs, because they are like fluorescent and that, but if you are trying to get a wheelchair down a knobbed slope, and get across, practically you've only gone a yard or so and it's already gone 4-3-2-1!

Besides the psychological benefits of being in a safe space among understanding individuals, Sam speaks, metaphorically, of the 'kinship'[22] existing among disabled people getting together at centres tailored specifically to them. 'Everyone has a problem similar to yourself: some of them may be worse, some of them may be not be as bad as yourself, but everybody's got that problem.' Sam does not meet his fellow charity users outside of that context, primarily because of the physical limitations imposed by his medical conditions, but he does speak fondly of the people he has met at Sunshine, whom he looks forward to seeing every week.

While the scope of his life seems to be expanded by his participation in these classes, his fear of life becoming more limited is triggered by the memory of an accident he had while taking part in a mainstream (non VI-specific) rambling group:

> *We were going along a canal bank, and people knew I had lost my sight, and I was walking along, and unfortunately there was a large metal ring, which is from years ago when the canal boats used to go along the canal. I never saw this very thick metal ring. One minute I was upright, and the next minute I was flat, spread out, flat down on my face, and I remember blood was pouring from all over me, my face, I remember putting my arm up, and I said: 'This isn't because I've lost my sight,' I think I said: 'I've tripped on the ring,' but obviously it was because I couldn't see the ring. Because it went through my head 'Oh, I may not be able to go to this group again, because they'll think I'm a safety hazard.' That was a stupid thing, it's the independence in me. And actually it knocks your confidence any time you have a fall. But in my mind it was: 'Oh please, don't ever say I can't come to it again.'*

In recounting this story, he points out that it was the 'independence in him' that made him lie about the cause of his fall: he wanted his fellow ramblers to think that his fall may have happened to everyone, that it had nothing to do with his poor sight. Independence is something that Sam lives by. Comparing himself to the fellow users of another charitable organisation he and Dave are part of, he says:

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[22] Cfr the elderly gay men described by Shokeid, who get together as a group of strangers in order to talk about their daily lives, but refrain from calling themselves a community or a family (2001:23–24).

Several people in this group have got carers, they get everything done for them. With us two, we look after ourselves, I've never had any outside help for us, so I find life very hard, because I have to be the nurse, the doctor, the… working out of what food we want.

Referring to the mobility problems experienced by both his brother and himself, he adds:

Everything in your day is very hard, and trying to keep your home reasonably clean and a bit clutter free so that we don't fall over. But we cope, and I hope we'll be able to cope, because it makes you independent, and life is not easy, but there are far worse people, and who wants to be a burden to anyone?

Sam refrains from being, in his own words, 'a burden' even on his family members. His nephew, who lives next door to him, has a full-time job and does not have much free time, but 'does what he can' to help him. For instance, he helps Sam with his shopping, which would be an endeavour if he had to do it by himself:

Going into a supermarket to buy food I find it now like hell, because they are not equipped for blind people, unless you've got someone with you, because with my eyesight, when there's shelves four or five high, I can't see packets, weights, prices, dates, and so the first time he [his nephew] took me there, and I went around, I was a couple of hours, because you can't find the items. Supermarkets are set up that you have got to kind of go all the way round, because when you go round, you will buy impulsively, and I used to take so long, queuing up to pay at the end, and there's people behind, and you are trying to pack the stuff so that it's not getting squashed and everything, and you feel stressed, because of the time, but I've learnt to say to the person behind the desk: 'I'm sorry, I'm partially sighted, I'm not quick,' and I found I do it as seldom as possible, because I don't like it.

Sam feels more like 'a normal person' when he shops by himself and gets the things he needs into one portable bag, but has resigned himself to just giving his shopping

list to his nephew, who can get everything done more quickly if he goes to the supermarket on his own. In fact, when I spoke to him, he did not remember the last time that he had gone to do the shopping with his nephew.

Sam likes to preserve his independence in his daily life, but he also treasures independence at an institutional level. When I reacted with surprise at his affirmation that he would rather not receive help in his home, he explained:

> *Because I find with lots of people then in the end, they are not attempting to do anything for themselves, they actually expect the National Health Service or social people to run their lives and everything, and you just become like an institutionalized person, and the struggling life is what keeps you going. And so there is a purpose every day when I get up that I've got to get us through the day, and it is hard, but I pray every day that I can carry on doing like… Survival has being the impetus for people since the cave man! And it's the only way that you learn how to survive, you have to adapt to the situation, and attempt to find the answers yourself.*

Sam's independence at all levels, however, is threatened by his physical frailty. 'The activities we do actually are based round the physical problems of my brother and myself,' he tells me describing his and Dave's present situation and, thinking about the future, he adds: 'I just don't wanna a fall.' He fears how much more 'awkward' his life would be if he fell and injured his shoulder.[23] When comparing his own situation to that of other charity users, Sam treasures the little independence he preserves, which is superior to that of other disabled people. Clinging to this small remnant of autonomy, however, is incredibly consuming. Having limited strength entails that Sam has to plan many things in advance, so as to be able to calibrate correctly the energy he puts into the different tasks he carries out. Also, he admits to falling asleep, physically exhausted, after getting home from Sunshine on Thursdays. Yet, the yoga and arts courses are to him 'the highlight of the week,' a week that is otherwise punctuated by a series of battles that he still prefers to fight single-handedly.

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[23] For an anthropological study of the fear of falls among the elderly, see Boyles 2016.

2.5 Being Visually Impaired between 'Kinship' and 'Hard Work'

The story of Sam's engagement with Sunshine is eloquent testimony to the benefits of being part of a visually impaired group on the one hand, and of the tension between receiving help as a visually impaired person and preserving one's independence on the other. Negotiating such conflicting needs is, I argue, a component of the 'work' that people with sight loss have to perform. I would like to dwell on both of these two issues in this section and the next.

In regard to the pros of being part of a visually impaired community, a young sunshine user fittingly said: 'Some people go to church, I come to Sunshine,' while Sam commented on the 'kinship' developing in a group of disabled people he regularly attended.[24] Medical anthropologists have conceptualised how people with the same condition may coalesce. For instance, Paul Rabinow coined the term 'biosociality,' which defines the new way of constructing identity that individuals and groups can develop around their medical condition (1996:99, 102). He suggested that such forms of sociality may enable exchange of information and give rise to advocacy movements (ibid:102). Along similar lines, Adriana Petryna spoke of 'biological citizenship' as the 'massive demand for but selective access to a form of social welfare based on medical, scientific, and legal criteria that both acknowledge biological injury and compensate for it' (2013[2003]:6). Both biosociality and biological citizenship refer to the claims that people affected by a specific condition make. Although I am aware that some people with sight loss may coalesce in order to advocate for their rights, in my research I was more struck by the sense of community that such groups provide to visually impaired people. This phenomenon has been reported to exist among individuals who share other types of social disadvantage (see for instance Howe 1990:218 on the unemployed). During classes, Sunshine users chatted about anything from a broken shower to performing arts

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[24] Cfr the HIV-positive gay men described by Bloom who, in order not to be stigmatised for their seropositive status, find social support in groups based on other common characteristics, such as alcohol-dependency (1997:468–470, 472).

shows, from the academic achievements of a grandchild to their favourite food, from medical malpractice to the latest Christmas party. They also felt free to discuss their medical condition and society's attitude towards its feeblest members, giving concrete examples from their own lives. In sum, they did what biological anthropologists call 'grooming at a distance' (see Dunbar 2010 and Arlet et al. 2015). Such sense of kinship was strengthened by the fact that some of the tutors were visually impaired themselves. One of them told me that her pupils felt that they were all part of the same club, and they could relate to her more easily because she knew what it meant to suffer from sight loss.[25] They also admired her ability to navigate across the city by public transport and to work full-time.

In fact, one type of relief that people with sight loss gained by frequenting Sunshine, or other groups of people with sight loss, derived from the fact that they all, to a greater or lesser extent, had to invest extra time and effort, in comparison to a sighted person, in a wide range of tasks. On this basis, they felt a degree of common understanding when they were among people who also had a visual impairment. I argue that, for visually impaired people, being aware that other individuals with sight loss also had to carry out this type of 'work' created a bond among them. I will now give a few instances of the multiple forms that this extra 'work' took. One of its most basic manifestations was the straining of their eyes, indeed their whole body, in order to orient themselves or make sense of the world around them. Depending on the severity and the nature of their visual impairment, they may tilt their head, tap their cane, and use auditory or olfactory cues. For them, a walk in the park acquired its metaphorical meaning only after several exercises in orientation. Concentration was constantly required outdoors as it was in the more familiar environment of the home. Dietlinde, the subject of the first portrait, said that, whenever somebody interrupted her when she was doing chores around the house, she asked them to give her some time to keep her chain of actions within working memory. A lot of 'work' was required when transitioning from the realm of one's own house to other places: checking the evening before where everything was, making sure to have everything that was needed when leaving for the day. My participants seemed to

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[25] Contrast this to the mentally ill people described by Estroff, who felt they could not gain impartial advice from people with the same disability (1985:179).

have no choice but being well-organised; their lives entailed 'lots of forward planning, lots more thinking and arranging, and being prepared.' As excellent planners, they rarely failed to be on time, or even early, for our meetings.

The negative side of the structured lives I have described above was a loss in spontaneity, and a higher degree of 'work' required to adapt to changes. This was not a matter of mere uneasiness in social interaction, rather it had repercussions on multiple domains of my participants' lives. For instance, loss of spontaneity meant that informants may find difficulties when their office relocated. The lack of spontaneity imposed upon them by sight loss also meant that their chances of getting a job were curtailed: 'I would be happy to go and work in a bar and get money that way,' told me Laila, an embittered participant, who worked in another profession only two days a week, 'but that is something that I can't do.' Even in the domain of leisure the palette of activities in which they could take part was restricted. Laila bemoaned the treatment she received when she tried to join a class organised by a popular online social platform:

> Like I want to do a zumba class and I've been wanting to do this class for about three months, and I don't know the area of Donchester where it is, I don't know where the location is, even though I looked it up on maps. The woman is gonna call me this afternoon, to just basically make sure she's not gonna get sued if anything happens to me. I think she's scared, but I try to get a volunteer to come with me, but I can't find one through the various networks that I know. So, you know, this is something I have been wanting to do and I can't do it, because, you know, I can't just rock up and turn up, which is what I'll do tomorrow, because if I don't go, I'm not gonna ever go. I've got money aside, and I am gonna get a taxi there. I'll speak to this woman this afternoon, and hopefully that will come into fruition, and hopefully once I do the journey a couple of times, I'll memorise where it is, and be ok. It just means that things are restrictive.

Volunteering was also difficult to access, which gave rise to more expenditures of energy. A participant expressed frustration at the process of applying for volunteering positions: 'Lots of people think: "It must be easy", what I am saying is:

"My experience doesn't hold up to this."' Although he had successfully worked as a volunteer on some occasions, he said he felt he had to put as much effort into finding volunteering positions as in the past he had had to put into applying for work posts. Besides the compatibility between himself and the roles on offer, he attributed his lack of success to his 'failure to persuade the organizer that they should accept [his] offer of [his] time.' He was cognisant that the adjustments that those who hired him would have to put in place may discourage them from hiring him. He was particularly disappointed when organisations did not even respond to his applications. It appears that, just as 'work' had to be carried out in order to integrate into the VI community, 'work' also had to be carried out in order to negotiate one's boundaries in interactions with the mainstream world. I will now expand on this topic, as it is fundamental to an understanding of why visually impaired people may feel stressed, if not discriminated against, in a world where sight is the norm and, conversely, find solace among other visually impaired people.

Sam's observation on 'kinship,' i.e. the relief of being among visually impaired people, can be contrasted to the comments that other participants made in regard to the ordeal of negotiating their visually impaired status in mainstream society. This issue was particularly acute among partially sighted people: when listening to their tribulations, I became aware of one more type of 'work' carried out by (in this case one particular type of) people with sight loss. Being not fully sighted but not totally blind either, they faced specific issues on how to use their remaining sight (see Taylor 1993 as a guide on how to adapt to partial sight). More importantly, they felt stuck between two worlds, and talked of the constant need to 'explain themselves' in their daily interactions with sighted people (see Kudlick 2011). This was especially true if they did not use any of the attributes that help members of the public identify them as visually impaired, such as a white cane, a guide dog or shades. One of my partially sighted informants commented positively on a man who wrote down for her in large characters some instructions, without making a fuss. However, she said this was the exception:

> *Whereas I think some people they want to know why you can't see. 'Why can't you see? Why aren't you wearing glasses?' and it's like: wait a minute, why? Do you go to a random person who's in a wheelchair and ask 'Why can't*

you walk? Why are you in a wheelchair?' Can you not just take for granted
that actually the person is just restricted in a way? That asking for support and
help you just give? That's another of my bugbears. I stopped saying to people
in shops 'I can't see very well,' because they just want to know why I'm not
wearing glasses. And you ask any partially sighted person, they'll probably
say the same. And you stop having to then almost justify the reasons for
asking for help. Whereas it's just straightforward: 'Just tell me what the price
is.' It can be exhausting, being a disabled person, a visually impaired person
[laughs bitterly]. It can be really, really, really exhausting.

Many comparable situations are presented in the medical anthropology literature.
For instance, Kleinman et al. observe that pain is 'absolute private certainty to
sufferer,' but may 'become absolute public doubt to the observer' (1992:5). Another
example is the liminality of HIV-negative people in serodiscordant relationships, who
are invisible in a world that they frequent, but of which they are not personally part of
(Persson 2011, see also Van der Straten et al. 1998). For people with sight loss and
other invisible disabilities, having to explain themselves (see Couser 2013:458) is
one type of exhaustion they have to endure, one more type of 'work' they have to
perform. A relief to such exhaustion was one of the benefits that Sunshine could
provide to its users, including Sam. Indeed, users were relieved from the burden of
carrying out this 'work.'

In some cases, the sense of kinship among people was not founded on the hard
'work' they all carried out, but on the easy-going interactions they had among
themselves, which encouraged them to learn from each other and to let all barriers
down. These relaxed social interactions benefitted people like Sam, who had to face
the burden of becoming blind in old age, but also people who had been born blind,
like Krish. Well-adjusted to his sight impairment, retired after a fulfilling career and
happy with his family life, he frequented Sunshine for reasons very different from
those of Sam, for whom joining this organisation also meant joining the visually
impaired community. Krish had been involved with sight loss organisations all his life
and, now an elderly man, he kept himself 'reasonably busy' by acting as a trustee for
a few of them. In this thesis I focus on the plight of visually impaired people living on

little work or none, but I also came across people with sight loss who, for very different reasons, did not want to work. Here are the reasons that Krish gave me:

> *When I arrived here [in the UK, nine years ago] I had opportunity of getting a job, but I said: no, I have had enough of it. I don't want to work for payment [sic] employment. I just want to work to keep myself fit, mentally and physically. And I want to work on my own terms, when I want to work, I work; when I don't want to work, I don't work. No compulsion, no tensions, no panic, with free mind. I work to the extent that I can. I take pressure to the extent that I should be taking the pressure.*

Free from commitments, Krish could enjoy the 'quality time,' i.e. social and intellectual stimuli he found at Sunshine. The same sense of 'kinship' that he found at this community may lead some visually impaired people (though not Sunshine users) to 'talk in a code' among themselves, or even to tell jokes about visually impaired people and address each other with non-politically correct terms, such as 'cripple' or 'blind bastard.' Such a way of bonding among people with a disability, which visually impaired people themselves recognise to be appalling in the eyes of today's mainstream society, has been reported by anthropologists elsewhere (see Bloom 2019:125). Devlieger, for instance, carried out fieldwork in a liminal zone in Kenya where lots of disabled people made a living (2018c). At the Beach, as this zone was called, words that would have been insults if directed by an able-bodied person to a disabled one turned into a bonding mechanism among the latter (ibid:168). As the reader will discover in the following chapter, this was common practice also on the shop floor at Spring.

A consequential type of 'work' was the one that visually impaired people did in order to stand up for their rights in a world where they encountered more or less overt forms of discrimination. 'What you have just seen happens many times,' told me Mona, a guide-dog owner, about the reaction of a shopkeeper, who was about to stop us from entering the premises, only to realise that the dog was a working dog, and therefore authorized to be inside. On other occasions, Mona told me, she had been less lucky: the manager had insisted on not letting her dog in, even though it was in harness. She told me she tried not to let these incidents mar her day. Other

participants were more explicit in their complaints. For instance, Dietlinde, whom I accompanied to buy a coffee machine, was adamant that the shop assistant takes it out of the box for her to feel it. She responded to the assistant's refusal by kindly but firmly explaining that staff was supposed to demonstrate the use of products in store. Another participant even got to name the 'hard work and emotional cost' required in these negotiations, a work that was otherwise not articulated as an emic category. He made the example of buying something in a shop. The higher level of reliance on others caused by his disability made him desire a series of qualities in the sales personnel that may not be essential to a sighted shopper. Their empathy helped, and so did their level of willingness and time available to assist. He concluded that the two extreme options open to him were to ask for the manager and obtain exactly what he wanted but get more stressed, or settle for a not entirely suitable product. His actual choices, he said, would fall somewhere in the middle of this range. This example illustrates what I mean by the multi-faceted, constant, at times gruelling 'work' that people with sight loss had to perform in their daily lives. This could be accompanied by attempts to raise awareness about how to attend to their needs better, in fact such education was seen as a way to counter the negative attitudes that made the 'work' necessary. I will expand on this topic in chapter 6.

As it has become apparent, having a sight impairment may cause people to struggle on a practical, emotional and social level. It should be noted, however, that sight impairment *per se* did not constitute an idiom of distress. Mendenhall et al. argue that their participants, who suffer from Type II diabetes, use their disease as an idiom of distress, i.e. they express psychological distress caused by social malaise through complaints about their ill bodies (2010). On the contrary, my participants seldom brought their symptoms to the fore and, when they did, their complaints were not used to unveil a deeper affliction. Such deeper affliction may exist, however, and my informants expressed their dissatisfaction with the structural injustices they were victims of or with the 'box-ticking' practiced by different organisations, including potential employers. This consisted in complying with equality legislation while in practice offering little accommodation and inclusivity (cfr Hartblay 2017). When my participants voiced their disgruntlement, they often did so through the social model of disability, which posits that 'it is not an impairment that creates a disability, but rather the incompatibility of impaired bodies with social norms and material environments

that are determined by the able-bodied majority' (Devlieger 2018b:1-2, see also Barton 1996:8 and Groce 2018a:1-2). Two pioneers of the study of the social influence on the categories of the abnormal were Ruth Benedict, who wrote on the 'abnormal' in different cultural settings (1934), and Joan Ablon, who carried out research on disability (1981, see Shuttleworth & Kasnitz 2004), especially dwarfism (1984). Moreover, Nora Groce did the ethnography of a locale where deafness had been so widespread that 'everyone [there] spoke sign language,' and deaf people were neither despised nor glorified (1985). Whereas workers at Spring had not heard of the social model of disability (although they may have absorbed its main message simply by living in the British context and listening to British media), most of my individually recruited participants proactively brought up this notion when explaining to me their experience of living as a disabled person in Donchester. The words of one of my interlocutors explain the gist of this model: 'I might have a disability, but it is not what is making me disabled. What is making me disabled is how society treats me and what society does and doesn't do.' The simplicity of this model and its origin in Britain (Shakespeare 2013:216) perhaps explain why my informants were familiar with it. In its most simplistic interpretation, the model advocates an onus on society to change and accommodate to disabled people's needs (ibid:217) but, as this thesis demonstrates, a great 'work' of accommodation was carried out in practice by the same visually impaired participants who embraced the social model of disability. It is unquestionable, though, that the principal ethos of such model, i.e. its emphasis on barriers posed by society rather than on the impairment, was strongly adhered to by my individually recruited participants. Just like the development of this model had historically given people with disabilities a stronger sense of collective identity (ibid.), so has it given my middle-class participants, who are more conscious of social debates, a common value.

The social model of disability is also apposite to explain why, when complaining about the treatment they received in some social situations, my participants did not mention the visually impaired/sighted binary. Throughout my fieldwork I listened attentively for words that may denote what group of people my participants juxtaposed themselves to.[26] Occasionally they referred to 'normal people;'

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[26] Cfr Estroff on how her mentally ill participants defined non-mentally ill people (1985:176).

sometimes, when talking about interactions in the public sphere, to 'members of the public.' Semantically, the word 'sighted' was rarely mentioned and, although 'able-bodied' came up more frequently, no single term was prevalent. When visually impaired people voiced their concerns, or even anger, they did not allude to non-disabled people. In fact, what most of them craved was a place in the mosaic of human diversity, rather than being 'special' (see Kudlick 2011). When my participants complained, they denounced the intolerance, inflexibility and, most importantly, lack of understanding and awareness that they came across in various individuals and institutions. Conversely, they thought that a sincere respect of the principles of the social model of disability would benefit society at large:

> *If you went to a place where all chairs were ten foot high, I am sure you would, in a way, feel disabled. It's not just for people with physical disabilities, but really everyone. So when we have chairs that can move up down to cater for people of different heights, I don't see why we can't have a society that caters for every kind of need.*

It has been said that disability is 'an inescapable element of human existence and experience' (Couser 2013:456) and, in this metaphor, Yussef, like many other of my participants, emphasised the benefits that accommodation would bring to all people, all of whom have their strengths and weaknesses.

2.6 'The Impetus for People since the Cave Man': The Independence Conundrum

Above I elaborated on the tension that permeated the lives of people with sight loss in mainstream society. This helped explain the solace that they derived from being part of a visually impaired community, a topic that I presented earlier in the chapter. Now I would like to deal with the tension that runs in parallel to the one discussed above: the one between dependence and independence. Independence was by far the value that my interlocutors mentioned most frequently. It was also the objective

of many charitable organisations.[27] I therefore decided to systematically ask each of my participants what independence meant for them in practice. One of my interlocutors replied: 'Independence means being able to be self governing and autonomous in everything that you do. No restrictions, no confinement, no limitations, no challenges, just being able to be and do.' She also pointed out that she was most independent in her own home, which was substantiated by the comments of many of my informants. Some of my respondents would emphasise the spontaneity that independence allowed (see also Murphy 1990:76-77), and that they had had to relinquish as their ophthalmological condition progressed. For others, their desire for independence was related to mobility, which is one of the life skills most compromised by visual impairment: 'I can go to a station and shout for a member of staff. That's what gives me my independence;' 'Being able to go where I want to go, when I want to go, and not have to rely on other people.' In particular, with reference to the fact that a guide dog is taught a limited number of routes, a guide-dog user told me: 'Guide Dogs gives you four routes. But life is not like that! I don't just do four routes!' Other participants focussed on the nefarious consequences of their own dependence on themselves and on their loved ones: 'If you are dependent on someone, there is a huge risk, that you won't come anywhere near to achieving your potential as a person. You will also drain the emotional, physical, and financial resources of someone else.' In other cases, my question elicited responses that were precious to me as a researcher more generally, as independence emerged as a key to uncover what mattered most to my participants:

> *Independence also means you can get out and about. Once you get that independence, of travelling, you are able to leave the house, go to the shops when you want, jump on a bus, go see your friend, get in a taxi. Independence can mean a lot to people in different ways, and everyone views it differently. Independence means freedom for me. I can go to what I like. If I did not have my independence I would not be able to do my awareness training that I do on sight loss, meet people and talk to them, you know, and*

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[27] See also Taylor 1993:39, who spurs people surrounding partially sighted individuals to foster their independence.

educate them about sight loss, and go into workplaces and educate about sight loss.

This quote reveals independence as pivotal to many issues discussed in the thesis: the fact that every visually impaired person is different (chapters 1 and 2), and the wish to educate others about sight loss (chapter 6). What I wish to highlight here, however, is the dilemma between being independent and being dependent, as it is the one that is more productive in a discussion on the 'work' of people with sight loss, in particular on the 'work' they carried out when negotiating if, or to what extent, to be part of the visually impaired community. Such 'work' was integral to the narrative 'work' of reframing their lives, and as such was culturally and socially embedded (see also chapter 4).

My participants were indistinguishable from sighted people in Donchester in their desire for independence, a value which is strongly connected to individualism. It is impossible to discuss this issue without putting it in the context of English culture, and in particular of a busy metropolis like Donchester. Scholars within (Miller 2015) and without anthropology have studied the English propensity for individualism. Among the latter, MacFarlane invokes historical contingencies to trace the origins of English individualism (1978). Although his analysis at some points risks falling into a circular argument (it could be simplified into 'the English are individualistic because they used to be'), his thesis does draw on a series of concrete factors, such as the legal one, to explain the phenomenon (e.g. a system of inheritance favouring the primogenitor, ibid:176). Among anthropologists, Daniel Miller also takes a historical approach to argue that the English are 'highly sociable and philanthropic in the public domain and circumspect and reticent with regard to the private domain' (2015:336). In her study of kinship, Marilyn Strathern contends that, among the main facts of English kinship, are the individuality of the person (1992:14), and the reproduction of individuals by individuals (ibid:53). Put differently, she notices that kin roles in England are simply the relational part of the individual whole (ibid:78). In sum, various authors concur in arguing that in England the self is 'independent,' as its ties to the community are looser than those of an 'interdependent' self and, unlike the latter, it defines itself independently from the particular social network it finds itself in (Markus & Kitayama 1991).

It may well be that one of the reasons behind the belief that 'every visually impaired person is different' discussed above lies this strong cultural influence. Individualism and desire for independence had practical consequences on the lives of my participants: it tended to increase the 'work' (in the broader sense of the term) that they carried out as visually impaired people, as we saw in the case of Sam. With the exception that they needed help with navigation, I was surprised by how little reliant my participants were on me, and by how much they took upon themselves. Some even insisted on doing things alone under unfavourable circumstances, for instance Dietlinde, who refused my help and carried a bulky and heavy bag all on her own. The reluctance towards relying on others, be them strangers or family members, particularly affects my informants, who need more assistance and help in a wider range of circumstances because of their disability. My participants treasured the opportunities and services offered by Donchester, which gave them the chance to do something autonomously. Some of them compared this offer to the more limited one available in their home country, or in Donchester in the past. On the other hand, they lamented that this metropolis was 'congested, crowded, busy.' As a consequence, a blind person told me 'We don't see people that struggle. Not only disabled struggling, also financial struggling.' This more hostile facet of Donchester made it less conducive to independence.

In a country and in a city were independence and self-reliance were prime concerns, visually impaired people could not accept dependence uncritically. In this regard, Dietlinde (chapter 1) told me 'Most of the time it is good to be totally self-reliant. Because everyone has got their own life, they all have busy lives.' Like other participants, though, she praised the assistance offered by the transport network employees, and by volunteers from charitable organisations who accompanied visually impaired users from the nearest station to the venue. Such help, she thought, was 'worth its weight in gold.' In fact, even for those people who found themselves at ease as part of the VI community, there was always a tension in their belonging to it. At the heart of this tension was the ideal of independence cultivated by both visually impaired people themselves and sight loss charities. The assistance that these organisations gave to their users was an integral part of their institutional ethos, but so was their desire to foster independence. Visually impaired people's

acceptance of such forms of institutionalised help can be explained with the fact that, in Britain, charitable organisations tend to step in when family and social networks fail. One participant once remarked that, as I was a researcher, she felt more free to ask *me* for help than her family members. Being dependent, even dependant on one's closest relations, was not considered ideal.[28]

Visually impaired people, however, were sometimes pushed by circumstances to be at the mercy of strangers. This may happen, for instance, when they got lost in the vicinity of their own home, which made them feel particularly vulnerable and stressed. Here is Dietlinde telling me about losing her way home when she once came back from the station at night, when her sight is particularly limited:

> *One evening I was coming back from an event. It was 9.30 and there was no one around, and I walked the wrong way, and I ended up completely lost, and I was really really upset, because there was no person around, and it was black black black, and I was in a residential area, nobody was out and about, hardly any traffic. I was really really worried; I knew I could not call my husband, because he was in a meeting.*'

Eventually, somebody found her, and hearing 'Can I help you?' dissipated her anguish. She gave the passer by her address, and he escorted her home. Andy (chapter 5) encapsulated the conundrum of relying or not relying on help in these words: 'It is independence if I can choose. If somebody is offering help, my independence is to say yes or no.' In Dietlinde's story, however, we saw her totally dependent on the benevolence of a stranger.

What is feared even more than lack of independence is becoming synonymous with dependence. When faced with a new challenge, for instance starting a new job, visually impaired people are keen on actively demonstrating what they can or cannot do, rather than leaving this assessment to other people's assumptions. The fear of being equated with a stereotype may also prevent individuals who have recently lost their sight from joining sight loss groups and from becoming part of the VI community

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[28] Cfr Bloch 1973.

in Donchester. This is because they feel very uncomfortable with being labelled as visually impaired. When Robert became medically retired, the social gathering he most dreaded was the coffee morning at his local charitable organisation. Created for the purpose of combating visually impaired people's loneliness, it made him feel part of a group of people whose demeanour he detested and whose social skills he deplored. He finds most visually impaired people 'poorly educated,' 'inarticulate' and 'discomforting in their behaviour.' He used the words 'guilt by association' (cfr Powell-Cope & Brown 1992) to describe his feelings towards them, which were actually complex and rooted in his personal history. He admitted to sharing some of the characteristics of visually impaired people that he loathed, but attributed his overall better social skills to his education. This was, ironically, provided to him thanks to his sight impairment. Had he not been visually impaired, considering his family background he would probably not have had the educational opportunities he had. Eventually, Robert did become a member of some sight loss groups, but he did so 'for functional reasons,' as he wanted to take part in sports and leisure activities for which he needed sighted assistance. His relationship to the visually impaired community is still uneasy and ambivalent.

A further reason why a visually impaired person may feel their independence curtailed when joining the visually impaired community is that this community, at least in Donchester, is led mostly by sighted people. Here is an excerpt from an interview with Andy:

> Q: In what ways do you think that there is a visually impaired community?
> A: I think the concept of a visually impaired community is there, but the reality is a completely different one. For me, a visually impaired community should be something that is driven, structured, organised, determined, and shaped by people with a visual impairment, as opposed to sighted people telling us what to do and think. And, unfortunately, that's the world that we live in. We end up facilitating a reactive and a passive attitude of people rather than standing up and saying 'No, sorry, you can't do that.'

The issue highlighted by Andy resonates with the neglect of disability expertise pointed out by some scholars (Hartblay 2020). Disability expertise is the capacity

that disabled people acquire to navigate different social interactions, in particular those with people, but also buildings and institutions, that take able-bodiedness for granted (ibid:S27, S30, S34). The concept also foregrounds the value of this expertise, which is often overshadowed by that of other experts, for instance designers of the built environment (ibid:S27-S28). Although few of my participants raised the issue discussed by Andy, there was a debate within the VI community, and in the VI media, on whether the new head of the RNIB, whose workforce consists of 93% sighted and 7% visually impaired people, should be visually impaired (see In Touch 2017). Eventually, the organisation appointed a sighted chief executive (ibid.). At the same time, it is important to consider that sighted people working or volunteering for sight loss organisations acknowledged their lack of first-hand experience of sight loss. For instance, a Sunshine employee told me:

> *I have to constantly be very aware that… I don't know what it's like. I don't know what it's like. I might do one day, but you have to be so careful not to… You have to be careful with your own language. You can't become complacent 'Oh, I understand because I work for a blind charity' [laughs]. 'Cause you don't know, and you never will, unless, until… if it does happen to you.*

If, from the point of view of some people, with or without sight loss, it would be desirable for the RNIB to have a chief executive with a visual impairment, it should not be taken for granted that people with sight loss can act as exemplars for other people with sight loss. Role models may inspire a narrativization of one's own life, as we will see in chapter 5, where Yussef cites historical figures as disparate as Helen Keller, Imam Hussein and Steve Jobs. However, models may fail to inspire or even backfire. Whenever such failed role models are visually impaired, this constitutes another crack in the visually impaired community, real or imagined (Anderson 1983). In a series of fictional letters to Helen Keller, a 19th-century deaf and blind woman who is still acclaimed in the world of disability for her achievements, Georgina Kleege counters the halo of sainthood surrounding her (2006b). As a child, Kleege resented Keller whenever she was encouraged to live up to her standards of achievement and her appreciation for life, all the more so because she was told that, unlike Keller, she was 'only' blind. As an adult, Kleege articulated her disapproval of

such role-model in these words addressed directly to an imaginary Keller: 'Your life story inscribes the idea that disability is a personal tragedy to be overcome through an individual's fortitude and pluck, rather than a set of cultural practices and assumptions, affecting many individuals that could be changed through collective action' (ibid:1). Kleege's anger is tamed by the realisation that Helen Keller was enmeshed in a socio-historical context that, while elevating her, also set her apart as not fully human (ibid:44). In sum, Kleege shows that, just as we can become trapped in our own emplotted lives (see chapter 4), so can we be misled by false role models.

From the above discussion it is evident that the relationship that visually impaired people have to the visually impaired community is fraught with perils and contradictions. It is also a prism through which to look at how they develop their sense of self in the face of sight loss. Although people with sight loss, in particular adventitious sight loss, may at first shun this community, they may see integrating into it as an important phase in coming to terms with their sensory impairment, hence the relevance of the topic of community to the whole thesis. In chapters 3 and 4 I will describe the narratives through which workers at Spring make sense of their position in society through employment, and through which they attempt to change people's perception of disability. In chapter 5, the topic of community will be the backdrop on which I will present the therapeutic emplotment of two men with adventitious sight loss. In chapter 6 I will show how Yussef and other participants reached out to mainstream society with the intent to encourage others to emplot their own difficulties into, as opposed to out of, their life narratives. In the concluding chapter I will offer a less polarised view of society in order to overcome the sighted/sightless divide in favour of a common humanity. As one of my participants cogently pointed out, visually impaired people may constitute a community, but they are also a minority. If the barriers between them and mainstream society are maintained — and VI-only organisations might be a way of maintaining these barriers — then the 'work' of understanding and integration needed to create an inclusive society becomes much harder. This particular participant remembered walking on the street one Sunday morning and being pitied by a passer-by. Deep inside, though, she felt happy and active, in fact she was going to meet a friend. She argues that if there are lots of activities for visually impaired people, as there are in Donchester, there is the

risk of creating a 'VI bubble.' The passer-by would have seen her in a more accurate light and as less pitiful if he had met her and got to know her. This is at the heart of chapter 6, where I show how visually impaired people use their own life stories to inspire others, whereas the broader implications of chapter 2 will become apparent in chapter 7, which centres on the overcoming of the boundaries between visually impaired and mainstream through common humanity.

Chapter 3. Working 'Inside' and 'Downstairs': An Ethnography of Spring

3.1 Introduction

I devoted the previous chapter to the visually impaired community in Donchester. This chapter centres on a setting that constitutes a community of its own: the shop floor staff at Spring.[29] This factory, which produces drinks and confectionery products, now employs people with a mix of disabilities, but was founded with the objective of providing work for people with sight loss. In this chapter I leave aside narrative in order to provide an ethnography of the world of the workers, as well as an analysis of why they were employed at this organisation rather than in mainstream employment. The factors explaining this phenomenon are essential to an understanding of how workers emplotted their time at the company, which will be the subject of chapter 4. In particular, the sociality of the workplace was the interface of professional work and non-professional 'work,' which at Spring were intrinsically linked. I will therefore present the two facets of work throughout the chapter, as opposed to in separate sections. I will conclude with the portrait of Jim, an elderly worker who later retired. His pride at what he has achieved is a reminder of the power of both narrative 'work' and work proper in the lives of all of my informants.

3.2 Spring: The Factory and Its Workers

The plant is a drinks and confectionery factory situated in an industrial park on the outskirts of an English metropolis. It consists of the following main areas: the shop floor, a canteen, a reception and offices. Most offices are located on the first floor, with the exception of the one used by the operations manager and a person in a support role, which are on the ground floor. All other areas are located on the ground

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[29] The name of the company and the type of product have been changed for confidentiality purposes.

floor, where there is also a first-aid room. This is sometimes used as a small meeting space.

The shop floor is a rectangular area evenly lit and devoid of smells. From the entrance, which connects the shop floor to the canteen, it is possible to see the whole space, which is relatively small and subdivided into sections by three narrow corridors marked on the floor by yellow lines. These indicate the areas that should be kept clear from chairs and other obstacles. The long wall to the right-hand side of the entrance is lined up to the ceiling with shelves of boxes. This area is known as 'the warehouse.' The rest of the space is occupied by workstations. These are organised around tables surrounded by chairs, or machines and their conveyor belts, which are small and quiet, and do not dominate the space either visually or acoustically. A variety of jobs can be carried out at the workstations, whereas at the machines drinks are bottled and bottles are labelled. At the very end of the factory, on the side of the rectangle opposite the entrance, is an enclosed space where drinks are made in large tanks. At the far end of the shop floor is another work station, where fudge is processed through a machine and chopped manually. Quite prominent throughout the shop floor space is the presence of cardboard boxes, which are filled with products or their components. Near the entrance there are two small pens for guide dogs, one of which barks when it feels disturbed. Occasionally, announcements are made over the loudspeakers, for instance to call someone to the office or reception, or to announce that the managers will take visitors around the building. One radio is positioned near the tables where people sit and perform various tasks, for instance pack products. It is always tuned to a radio station broadcasting songs from the 1960s or 1970s, which are to the taste of the workers, most of whom are middle-aged or elderly. When they are not sitting quietly or chatting to each other, they sometimes sing along, or make comments on the songs. The atmosphere at Spring is in fact quite relaxed and friendly.

There are usually three 'line-leaders' in charge of assigning the workers to a work post and a particular task, as well as of guaranteeing the smooth running of the production. They usually walk around to maintain an overview of what is happening on the shop floor, although sometimes they are required to join the workers in the completion of a task. Around 20 to 30 people work on the shop floor at any one time;

the majority of them wear a white long overcoat over their everyday clothes. Most of the workers are visually impaired; some have another type of disability, for instance a hearing impairment or a learning difficulty. There are also able-bodied people facing difficulties in gaining employment because of other reasons. On the shop floor, middle-aged people outnumber elderly people, who in turn are more numerous than young workers. The proportion of men to women is approximately 3:2.

When workers are not on the shop floor, they can be found in the adjacent canteen, which is the other main space. Here there are various small tables, each accommodating up to four people, and two longer tables. People tend to sit in the same place, or at least in the same area. Some usually sit alone, some with one or two other workers. Apart from eating, here people sit quietly or chat. Sighted or partially sighted people may also read free morning newspapers. Workers can access their lockers, which line the room. Some people look at their smartphones or use their basic mobile phones. These devices are not allowed on the shop floor. The canteen can be used also by some members of the administrative staff who come downstairs to have their lunch. The offices on the first floor are connected to the ground floor by two sets of stairs. One directly connects the offices with the shop floor, and on the same wall where it is located there is a window that allows staff in one of the offices to look onto the shop floor. The other set of stairs is near the reception, where the receptionist sits at a desk facing the main entrance. This is, as it would be expected, a place of transit, with people going in and out of the main door frequently, in particular at the beginning, middle and end of the day. Reception is also a place where all employees, regardless of their role, are brought together visually, as their photographic portraits and names are displayed on a board alongside the year when they joined the company.

People at the factory have different levels of sight, and cope with their work tasks in different ways. Partially sighted people may bring objects close to their eyes, or tilt their head to bring the object into their field of vision. People who have no sight at all may just perform a task without the help of their sight, while their hands work expertly. I observed a worker who had little or no sight: he proceeded with his task mechanically, keeping his gaze fixed ahead of him, even when he lengthened his arm to the right in order to drop the finished box into a larger cardboard container.

Since not all workers are affected by sigh loss, blind and partially sighted people can also consult people with sight, or with more sight than themselves. This happens constantly at an informal level, but one partially sighted line-leader has formally applied for a sighted support worker through Access to Work (see chapter 1). It should be noted that, although some partially sighted workers wear thick glasses, workers generally do not use particular tools to facilitate their seeing. An exception is a worker whose job entails reading paperwork, who has an enlarger that magnifies the text put under a lens and displays it on a large screen. He told me about how straining this process is for his eyes. However, the effort that people have to put into work because of their visual impairment is not usually talked about.

Something that workers discussed more frequently during my fieldwork was their professional history. All of the workers who were part of my cohort were in school until the age of approximately 16, although some underwent some training sometime during their lives, for instance taking vocational, numeracy, literacy or IT courses. It is apposite to briefly trace the professional trajectories of some of them. One worker was at his 4th job, having previously worked in both sheltered and mainstream companies. He was congenitally blind and very proud of his strong work ethic. 'I finished college on Friday and, believe it or not, I was working on Monday,' he told me more than once. Another worker was employed in a mainstream factory when he lost his sight. After a few years, he found a job with the present company working in basketry and, when that division was closed down, he took the job he has now. A congenitally partially sighted person held for two years a job in an organisation that was not a supported business, but whose managers were open towards disabled people, having a disabled child themselves. In 1980, when his sight deteriorated and prevented him from reading, he went for an assessment and was given a job at Spring, which was then known by an acronym that in this thesis I have changed to 'BBM' for confidentiality purposes. He retained the job for ten years, and then started working at another charity-run 'workshop.' When it closed down, he came back to the factory, which had by now changed its name to 'Spring,' on a two-day-a-week placement. Other workers had spent their entire professional lives working in sheltered businesses. For instance, one used to work at another 'workshop' and, when he was made redundant, he found a job at Spring, where he had been working for eleven years when I met him. Another worker left school at sixteen and took

additional short-term courses, but after that he was out of work for ten years. He eventually found a job in the basketry division of the present company and, when that line of production was terminated, he opted for his present job in the drinks and confectionery division rather than redundancy. In his own words, he had 'only worked with disabled people.' A similar story was that of a partially sighted worker who left school at 17, went to a rehabilitation centre, and then was at home for eight years. She later went to a day centre for two years, which helped her find her present position in 1982. A congenitally blind worker, who started his professional life in 1979, worked over the years for three separate 'workshops,' and had been at Spring for ten years. Like him, the receptionist had worked only in sheltered environments, but for a single company: 'I've only worked here, my work experience for other companies is nil, apart from supported employment.' In some of the above cases, the transition from one workplace to the next was motivated by redundancy. This was particularly painful in the case of an adventitiously partially sighted worker who had been made redundant from his company, which was a local authority-run 'workshop,' after 35 years of service and just six months before he could have claimed his old-age pension. However, he found a job at Spring just one year afterwards.

The above are the professional trajectories of some of the fourteen visually impaired workers who took part in my research project. Most of my participants were middle-aged or elderly, and were on a permanent contract. They therefore belonged to one of the two main categories into which workers at Spring fell: they had been with the organisation for a long time, sometimes 20 or even 30 years, and usually worked four and a half days a week. They were supported through different schemes, for instance Work Choice (more about it just below) or local authority grants. The second category of workers were employed on a six-month contract as part of a Government scheme aimed at getting people into work called 'Work Choice,' which was run by an employment and training provider named Seetec. These employees worked a sixteen-hour week. Which subsection of the workforce a worker fell into depended primarily on the programme through which the person had been hired. This in turn depended on the historical phase the company found itself in when the person was recruited: the grants that supported the former category of workers were being phased out, as were permanent contracts as a whole. Broadly speaking,

permanent and temporary employees, whose time horizons at the factory were different, corresponded to the two main objectives of the company, namely providing work for individuals who would find it difficult to find jobs in the 'outside' world, as it is often called by workers themselves, and being a stepping stone towards mainstream employment, respectively. This difference in employment did not affect the way workers worked on the shop floor: all took part in the production, which I describe in the section below, in the same way.

3.3 'We Are the Only One Remaining': Spring and 'Blind Workshops' in Britain

If the previous section was a static description of Spring and its people, this presents the activities carried out on the shop floor.[30]

> *I am sitting at a table; the line manager comes to bring me some flat cardboard so that I can make up boxes, into which products will then be put in order to be sold. 'Have you done this before?' I haven't, so he takes one to show me. 'You bend this here…' I take another and start doing the same. We fold all the different parts until the box is neatly made. It has taken me probably less than one minute to learn. I do not think that, during my time at the factory, it has taken me longer than this to learn any one task. 'Take it easy. No rush.' He tells me, as he walks off. I start making boxes, only lifting my gaze to observe the vast factory space. To my left, sitting at the same large table, a female worker folds another piece of cardboard, and puts it into the boxes I have made. This separates the box into different slots, into which the products can be inserted. She is visually impaired, and helps herself in the task by bringing the box closer to her face in order to see better. At another station a few metres from us, an 'In Work Support' officer completes the job by putting products into the box. She is responsible for helping workers find jobs elsewhere and her role is office-based, but she sometimes joins us on*

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[30] During my fieldwork, a new CEO and management team were appointed. As I explain later in the text, they started to implement different changes. Since I experienced only some of the new policies that would be gradually introduced, I use the past tense in the rest of this chapter to make clear that I refer to Spring as I knew it when carrying out my research.

the shop floor. I continue to work, until boxes pile up by my side. The lady to my left has to leave, so she asks me to do her job as well. 'Do you know how to do it?' She shows me step by step. Again, knowledge is passed on in around twenty seconds. I continue to make boxes, a task that will take up the whole of the afternoon.

In this vignette from my fieldnotes, as well as in the description of the factory I provided above, the reader may have felt plunged into a different world. Indeed, as an ethnographer, I felt Spring was a special workplace. Many factors contributed to Spring being very different from a mainstream company. First of all, Spring was unlike a modern factory. The word 'factory' evokes a production site deploying primarily machines. At Spring, however, their role was ancillary to that of people. Many production steps were not automated, leading to a great number of workers being involved in the completion of a simple task. The following vignette, taken from my fieldnotes, illustrates the sub-division of the production process, and also the types of jobs that workers normally performed. It should be said that various workers could perform various tasks and were quite flexible in terms of what job they did, while others tended to stick to the same task.

In the production line, I observed:
1. One person putting empty bottles on a conveyor belt.
2. Two people putting tops on the bottles.
3. One person putting bottles in a box.
4. One person moving the bottles from the box to a tray.
5. One person taking the tray to another line.
6. One person putting the tray into the wrapping machine.
7. One person checking that the tray stays upright (I was told that otherwise the bottles would topple over).
8. One person labelling the wrapped tray coming out of the machine.
9. One person putting the labelled, wrapped tray with the labelled bottles into a box.

On another occasion, I observed the following:

1a. One person separating the plastic holders that will hold the tube, which contains jelly, firmly inside the box (these plastic holders tend to stick together).

1b. One person taking a flatpack and making up a small box for each of the finished jelly tubes.

2. One person taking the jelly tubes, inserting each of them into a plastic holder and putting them into a small box.

3. These small boxes are then put onto a conveyor belt by one person.

4. Each box, wrapped individually in cellophane, comes out at the other end. One person receives it and puts it onto a tray.

1c. In the meantime, a big cardboard box has been prepared as the final package by a person who puts some cardboard separators inside, so as to create a slot for each of the twelve small boxes it will contain. The final box has labels, which were attached to it, in a previous phase, by another person.

6. Another worker puts the cellophane-wrapped small boxes into the big cardboard box.

7. Again another person seals this final box with a tape gun.

In addition to the steps outlined above, some workers had to correct the work performed by the machine: because the labels of the products coming out of the conveyor belt were often creased, some workers performed the task of manually peeling off the label and sticking it back on. While mainstream factories are increasingly been automated, Spring seemed to have gone in the opposite direction. For instance, big boxes of products were wrapped in cling film manually. When I asked about this procedure, I was told that it used to be done by machines, but not anymore.

In spite of its heavy reliance on manpower, the plant could not be regarded as a manual workshop either. The visceral attachment to the material (Sturt 1963[1923]:202) and the knowledge developed over the years, if not over the centuries (ibid:19, 31), that pervade artisan production units were absent. 'Guess work' (ibid:198) and 'art' (ibid:19) may be glimpsed in the trick a worker has discovered to complete a task more quickly, but did not permeate the shop floor or unite its workers in a learning community that took visible pride in the final product.

'Nobody taught me really, it's very simple, they just clip on!' a worker explained to me when I asked him from whom he had learnt to do the job he was performing, i.e. putting tops on bottles. Instructions were given by line leaders to workers, passed on from worker to worker, but without the emotional glow that brings together those who feel they are each an indispensable contributor to a collective masterwork. In fact, workers were silent on products, which, as the chapter progresses, will appear as invisible material catalysts of a powerful social reaction.

The management was aware that they 'could save a shedload of money if [they] automated and invested in machinery,' but they were also aware that that was 'absolutely not the point.' Lack of automation, as well as sub-division of the workflow, relate to the focus of the organisation on its workforce rather than its output, and on its ethos, which was to provide 'meaningful employment' to people with disabilities. The new CEO emphasised the importance of taking into account their different abilities. Not everybody 'putting caps on the bottles does it at the same speed,' he said, using the rhythm of the production as an example. Indeed, speed was one of the factors that set Spring apart from the hectic lifestyle of Donchester. 'Take your time,' I was often told when, as a participant observer, I was asked to complete a task. Primed by the fast pace of the city and its striving for productivity, it took me a while to adapt to an environment where there was 'no rush.'

Related to the low level of automation, what also made Spring special was the 'big divide' in IT literacy between its workforce on the one hand and mainstream companies on the other. This was pointed out to me by one of the few workers with good IT skills. During my fieldwork, even those participants who had received some workplace IT training in the past admitted to having lost this skill because they were not required to use it at work, and because they did not use it in their personal lives either.

All of Spring's singularities outlined above help explain the separation articulated by the workers between 'inside,' i.e. Spring, and 'outside,' i.e. the mainstream world of employment. This divide is at the heart of the narratives articulated by workers themselves, which will be discussed at greater length in the following chapter. Many workers expressed great doubts in regard to their likelihood of getting a job outside,

should they have to or want to quit the factory. The main reason why they thought they would be unable to find work outside was mainstream companies' inability, or unwillingness, to absorb a disabled workforce. This concern was voiced at all hierarchical levels at Spring. The ex-CEO told me in our interview: 'I'd love there not to be a need for Spring: if every organisation was adaptable and as conducive to employing people with disabilities, then fine, we'll say "our job is done", and we'll shut the doors, but I don't see that happening any time soon.' This was echoed more concisely by the new CEO: 'Like any charity, we should put ourselves out of business.' Their view was shared by the workers: as one of my interviewees said: 'But it is difficult, there are people [the 'in-work support' officers] upstairs who do searches for people, looking around for jobs for people, but, as I said, it's not so much the people here, *it's the employers out there*' (my emphasis).

Although both workers and the management blamed mainstream companies for their inability to absorb a disabled workforce, it is now apposite to shed light on Spring itself. Tracing the historical development of blind workshops in Britain and outlining how Spring is situated within this trajectory helps to explain the distinction between inside and outside, which is central to the discussion on the workers' narratives presented in chapter 4. The term 'blind workshop' is frowned upon by both the current and the preceding CEO, and the ex-factory manager called it 'a horrible word.' Their revulsion is justified: in his history of the blind in British society, Gordon Phillips describes how such organisations were created in the same zeitgeist that gave rise to workhouses and lunatic asylums (Phillips 2004:18). The new company managers would rather present Spring as a 'social enterprise.' Historical blind workshops may be regarded as 'total institutions' according to two of Goffman's definitions (1991[1961]):15-17): because they have a professional purpose (ibid:16) and because they 'care for persons felt to be both incapable and harmless' (ibid.). However, they did not all conform to a strict institutional pattern (Phillips 2004:19), nor did they share the same operational model (ibid.). Nevertheless, broadly speaking they all had an important goal: channelling the labour of blind people (ibid:44) in order not only to fight idleness (ibid:48), but also to guarantee them an income (ibid, ibid:26). They did so by concentrating on the manufacturing of specific products, and basketry (ibid:118) and mattress production (ibid:53) became strongly

associated with people with sight loss in Britain. In fact BBM, the company that later became Spring, used to produce baskets.

While retracing the history of blind workshops in Britain is beyond the remit of this work, identifying its key features may help understand Spring. There are characteristics of blind workshops that strikingly resemble the situation I found at Spring. For instance, since the first half of the 19th century, mechanisation competed with the manual production of blind people (ibid:65), just like in the 21st century workers are aware that automation would threaten their jobs. Again, even in the early history of workshops there was a perceived chasm with the competitive world outside (ibid:67). Indeed, there was a fear that the inward looking nature of the institution would impair its inmates' insertion into the 'outside world' (ibid:88) and into mainstream employment (ibid:101), a fear that was shared by all echelons at Spring.

What also emerges from Phillips' book that is important for the present discussion is the fact that, for over a century and until the 20th century, 'the problem of blindness had been considered chiefly as one of employment' (ibid:399). In fact, in 1869, just a few years after it was established, the organisation now known as RNIB incorporated the word 'employment' into its name, which became: 'the British and Foreign Blind Association for Improving the Embossed Literature of the Blind and Promoting the Employment of the Blind' (RNIB n.d.c). Even today, the threat that sight loss poses to employability looms large in the discussions taking place within the blind and partially sighted community. In parallel to that, Spring developed from a 19th century charity aimed at making blind people self-supportive through employment. During the 20th century the company, which has relocated its plant a few times to different parts of Donchester, shifted its focus from basketry to drinks and confectionery, and changed its sales strategy as times progressed. At the time of my fieldwork the company employed over 100 people, including sighted and visually impaired people, and around 80% of its workforce, at all levels within the organisation, had some form of disability. Defining the world of non-mainstream employment in Britain is made complex by the fact that various Government programmes have been put in place, in turn, over the course of the past years (see Gilbert et al. 2013). The terms under which these programmes are known 'change like the wind,' in the words of the new CEO, but they are all aimed at integrating disabled people into the mainstream

workforce. In the midst of this complexity, Spring can be regarded as a 'supported business,' i.e. an enterprise 'where over 50% of [the] workforce have a disability' (BASE n.d.). In this thesis, I also use the term 'sheltered' employment as a generic expression referring to all forms of non-mainstream employment. Spring is also a 'social enterprise,' i.e. an enterprise with a social (or environmental) mission (Social Enterprise UK n.d.).

In spring 2018 the company found itself in a phase of 'aggressive growth,' and later during my fieldwork I witnessed the appointing of a new CEO and an overhaul of the leadership team. For instance, the human resources manager and the factory manager changed. Nevertheless, there was some inertia in the way such changes affected life on the shop floor. It was only months after the change of leadership, for example, that new work hours were introduced. The restructuring of Spring had started in the early 21st century with a period of contraction, cost-cutting and redundancies characterised by a rigour that, incidentally, was not unheard of in the 19th century (see Phillips 2004:128, 192). Permanent contracts were no longer issued: instead, employees were hired mainly on a renewable six-month basis as part of Work Choice. This Government programme[31] provided 'work entry support' (Gov.uk n.d.b), i.e. 'advice on work and personal skills' helpful to find a job (ibid.). The introduction of Work Choice also meant that individuals interested in getting a job at Spring could not apply directly with the company, but had to go through this system. Because of the particular referral procedure that directed people to Spring to work on the Work Choice programme, the number of visually impaired workers had decreased in favour of people with other disabilities. Although, in principle, the longstanding workers, most of whom were visually impaired, could also use Spring as a springboard to mainstream employment, in practice they regarded it as the sole organisation where they could be employed, as it will be explained better below and in the following chapter.

In this thesis I use the term 'blind workshop,' or 'workshop,' between inverted commas whenever I refer to a contemporary organisation. My aim is to remind the reader that the chequered history of these institutions has little to do with today's

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[31] The programme has since been terminated and replaced by the 'Work and Health Programme.'

companies like Spring. The patronising, old-fashioned nature of workshops was repeatedly highlighted by senior members of staff at Spring, who preferred to use altogether different words to refer to their own and comparable contemporary organisations. Unlike the management, however, my participants were not reluctant to compare their company to blind workshops, in fact they frequently said 'we are the only one remaining' in reference to the fact that Spring was the only organisation created as a blind workshop that had survived in the city. Indeed, the roots of the company were in the same Victorian philanthropic ideals described by Phillips (2004). The sense of survival that transpired from the expression 'we are the only one remaining' was also explained by the massive closure of blind or disabled Remploy factories in the city, which provided work for people with disabilities (Brindle 2013, O'Hara 2017, Ramesh 2012). This was caused by a Government decision to withdraw the support it had been providing to these organisations, and to support the incorporation of disabled people into mainstream employment instead. The Remploy incident was palpable for my participants at Spring, who rubbed shoulders with workers who had been hired by the company after they had been made redundant from Remploy-run companies. More alarmingly, they heard from them stories of people who never found work again after redundancy. Although it has been pointed out that being part of a social environment where unemployment is widespread may soften the blow of job loss (Grint 1998:38), in the eyes of my participant, the Remploy redundancies justified their worries, indeed their certainty, that they would not be able to find work outside.

If the first asylums were set up 'to rescue the blind from destitution and mendacity' (Phillips 2004:328), what role did a job at Spring play in the workers' life narratives, and what did 'meaningful employment' mean for them? I will answer these questions in the following chapter, whereas below I will lay the foundations for this discussion by explaining the reasons for which some workers had been with the company for so long. I will devote the rest of this chapter to the various facets of this issue just because at Spring the interface between inside and outside was a dominant topic of discussion for the workers, as well as for the management.

Four main factors seemed instrumental in maintaining my participants at Spring within the confines of the factory. Firstly, the fact that the factory gave them the

temporal structure of a mainstream job helped them feel integrated in a society where being time-rich is seen as suspicious, especially in the professional arena. Secondly, their educational background made them employable in only a narrow range of fields, and their class background made them less willing to take up white-collar jobs. Thirdly, the financial gain was important, although the trade-off between salary and benefits had to be carefully assessed. Fourthly and importantly, the socialization happening on the shop floor made the factory much more than a workplace, and the jobs at the factory, in spite of their repetitiveness, much more than 'bullshit jobs' (Graeber 2018). I will deal with these four points in turn.

3.4 What Kept Workers at Spring

3.4.a Temporal Framework

At Spring, work time is structured as it would be at another company. During my fieldwork, the day started at 8.00 am and finished at 4.30 pm, with a break from 10.00 to 10.15 am for tea and from 12.30 pm to 1.20 pm for lunch. A buzzer marked the beginning and the end of work shifts and, although comfort breaks were allowed, it was not permitted to leave the workspace outside of work hours. The minutes spent waiting for the buzzer to go off before tea break, lunch, and especially the end of the day were charged with quiet expectation. Workers checked their watches: some brought their talking watch to their ear, and pressed a button to make the watch tell the time. Others, who had some sight, brought their watch, which had large black hands on a white background, closer to their eyes. Others again had Braille watches, where they could feel the clock face with their fingertips. Some workers did not feel the need to have their own time piece, and simply kept track of time by listening to the communal radio. When break time approached, they often interrupted their work, the severely sight impaired found someone to lead them, and walked nearer the exit to the canteen, though not too near, and stood there, in silence or speaking softly, waiting for the buzzer to go off. Before the end of the workday the radio was sometimes turned off a few minutes before the sound of the buzzer, and the stillness that fell on the factory floor made the waiting more dramatic. Towards the end of my fieldwork, work hours were extended in order to exactly

match the time workers were paid for. In fact, up to then the workforce had enjoyed a favourable treatment in this regard. This decision was controversial, but what remained uncontested, and undiscussed, was that, even regardless of the workload, there should be a separation between time spent on and off work, as well as on duty and on holiday.

There was a slightly rhetorical discourse on punctuality at the factory. In particular, I remember a worker saying that he had been late only twice during his long career at the company. When I saw him come late on a couple of occasions, I realized this may have been an exaggeration, but what matters for the purpose of this study is that punctuality was used as an idiom for commitment towards work. Indeed, clinging to a temporal framework is something that many of my visually impaired participants at the factory desired to do. In this regard, it should be noted that most workers had a long journey, sometimes with multiple transfers between trains, underground trains and busses, to and from work. Because this workplace was 'the only one remaining' among those that had existed to provide work for people with disabilities, workers came to Spring from all over Donchester, whereas in the past a network of similar organisations meant that it was more likely for them to secure a job local to where they lived. It took quite a few of the workers over one hour to reach the factory, indeed one of them told me that he considered himself 'lucky' that his journey to Spring only took about one hour each way on average. Some workers got up as early as four or five am in order to have ample time to go through their morning routine and travel to work. Besides using public transport, another way of commuting was to use Access-to-Work-sponsored minicabs, which made the journey less strenuous, but more unpredictable because of traffic jams. Still, factory workers often praised their job as an opportunity to get out of the house in the morning and contrasted it to be 'sitting at home doing nothing.' The empty time of days spent at home 'watching telly' was shunned. However, workers were aware that even at the factory 'some days [were] good, some days [were] slow': sometimes, when the shop floor was not very busy, workers had to come to terms with being bored at work. They checked their watches to punctuate a dull day, and one could not help noticing that the 'latest news' broadcast on the radio was the same as one hour earlier, an ironic counterpart to a monotonous workday.

Temporality has been an apposite lens through which anthropologists have looked at labour relations in different ethnographic settings. In this regard, my ethnographic context can be compared to that of the Brazilian *catadores*, the people who make a living looking for and selling recyclable materials in rubbish tips (Millar 2014). Many of those who leave this trade after finding a salaried position surprisingly decide to give up the structure of wage labour in order to go back to the dump. The decision to relinquish a more respectable job offering much better working conditions is due to the workers having become accustomed to deciding 'when and how much to work' (ibid:39). They are independent not only from a boss, but also from a schedule (ibid:44). Besides, they find 'the requirement to remain at work, while not working' 'absurd' (ibid:33). In contrast to this, Spring workers endured long periods of idleness when production was slow, thus suggesting that the 'doing nothing' at work was different from the one at home. It may have been inconclusive if considering the physical output of their work, but productive from another perspective. As Pickering phrased it in relation to the Lakota's attitude to temporality and work, besides waged labour there are 'other activities that may or may not appear economic from the viewpoint of the federal government, but nonetheless secure future access to and participation in social ventures that generate material necessities of life' (2004:92). When taking into account the importance attributed to 'getting out of the house' and, more importantly, sociality, being on the shop floor, even on days when the work rhythm was slow, was productive from the point of view of the workers. 'Somebody said: "I get bored." I said: "You can't do anything about it. You don't feel guilty about it. You are still being productive, you are still talking to someone."' In this sentence from my fieldnotes, a worker displayed an understanding of productivity very similar to the Lakotas'.

A more detailed acquaintance with work practices at the factory reveals that the work schedule was treated flexibly so as to allow workers to meet life necessities caused by their disability, such as attending hospital appointments. Once I saw a line leader give a worker permission to attend a visually impaired fair that he had just learnt about. The leave was granted on the spot. Thus, what on the surface distinguishes *catadores* described by Kathleen Millar from Spring's workers masks a common need. The *catadores* prefer to work on the dump because they can leave it without notice in order to tackle the insecurities they face in other domains of their lives as

urban poor (2014:34, 46); Spring's workers know they can count on the company's willingness to accommodate to their last-minute needs. As these needs are due to a variety of medical conditions, we can interpret Spring as the opposite of the neoliberal workplaces described by Molé. Whereas the latter created a climate of precariousness that resulted in *malaise* among its workforce, which manifested itself 'on the skin', i.e. work-related illnesses (2008), the former accommodated to the workers' ailments by granting them more flexibility. This is a degree of flexibility that the workers feel they would not find in mainstream employment, and one that is particularly important considering their multiple afflictions. Lenore Manderson and Narelle Warren have called 'recursive cascades of ill health' the co-causality between chronic conditions and the recurring health problems that accompany them, as well as the other structural problems they are often entangled with (2016). This concept is very much applicable to the workers I met at Spring. One worker, who had a physical as well as a visual impairment, told me that what hindered his personal and professional life was not his congenital ophthalmological condition but his other disability, which he had acquired as the result of an accident. Another worker pointed out to me, 'some people here have fits, others have diabetes. It's not just the eyes.' In fact, throughout my fieldwork it was not unusual for workers to be absent because of medical problems unrelated to their ophthalmological condition. Some of them even had to attend to family members with conditions as complex as their own, thus having to start a 'second shift' (Hochschild & Machung 2012) when they got home. But, as the worker quoted above told me, 'here everybody understands.'

3.4.b Educational Background and Social Class

The second factor that kept workers at Spring, and more specifically on the shop floor, was a series of characteristics that would work against them in the job market even regardless of their disability: age, education and social class. I would like to focus on the level of education and class background, firstly because class is considered to play an important role in British society (see Roberts 2011) and education is instrumental in the perpetuation of class differences. Secondly, I focus on these two factors because they were, indirectly, articulated by the workers themselves. In order to understand this point, it is apposite to introduce the distinction that, besides the inside-outside one, recurred in the workers'

conversation. It is the one between downstairs and upstairs, i.e. between the shop floor staff (as well as the receptionist), who worked on the ground floor, and the office workers, who worked on the first floor. Once, a meeting of 'upstairs' people was announced on the loudspeaker and, when I asked a worker for elucidations, his answer was: 'It doesn't bother us.' Similarly, when I asked one of the two receptionists (someone who was not visually impaired, but still part of the 'downstairs' people) for directions to the office of one of the 'upstairs' staff, he told me he had hardly even been upstairs. He didn't even know the exact location of an important manager's office, which made me wonder how he could, in his capacity of receptionist, direct staff or visitors to the right office.

As a researcher, I was allowed to go upstairs to interview the in-work support officers and the CEOs but, with the reservations that need to be made given my own social and educational background, overall I was part of the downstairs people. Whereas over the course of my fieldwork I did most of the jobs available on the shop floor, my knowledge of the world upstairs was limited. Still, I can say that upstairs there did not seem to be any visually impaired people, although I was told that there were people with other, visible or invisible, disabilities. Also, people upstairs were, on average, younger and, I suppose, better educated and more IT-proficient than the workers.

During my time at the factory there was an attempt by the management to overcome this division. Indeed, the 'upstairs people' were the ones in a position to reach out to the other section of the workforce, as their higher status conferred upon them the right to come downstairs.[32] The workers, on the contrary, could go upstairs only if summoned. The 'upstairs people's attitude was friendly, they knew most of the workers by name, and some joined the workers in the canteen to take part in the weekly raffle, or went to the canteen to ask them to sign cards, for instance for members of the team upstairs who were leaving their job. Moreover, both CEOs walked around the shop floor to say hello and have some small talk with workers roughly once a day whenever they were at the factory. The new CEO was also going to implement a new communication plan when I left the field, with the intent of

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[32] Cfr Estroff on the asymmetrical relationship between clients, i.e. people with mental illness, and 'inside normals,' i.e. non-mentally ill individuals willing to interact with them (1985:182).

making managerial decisions more transparent to the whole workforce. All in all, though, the divide between 'upstairs people' and shop floor staff was apparent. Only a few people were truly part of both worlds, notably the in-work support officers, who helped workers (mostly temporary staff) in their job search, and the person in charge of distributing payslips, who walked around the shop floor with the same zest for camaraderie that characterized the workers.

Although the distinction upstairs/downstairs is as clearly articulated as the one between inside and outside, only the latter was evoked by the workers when they discussed their lack of 'mobility in employment' (Friedner & Osborne 2015:10), i.e. their reasons for having remained in supported employment at Spring for so long. In other words, whenever their professional ambition, or lack of it, was articulated, it was expressed not as a vertical expansion, i.e. a promotion to a higher position, for instance to a managerial role, but as a horizontal one, to a comparable job outside, or at most to areas of the shop floor that were considered more sophisticated because of the tasks that were carried out there, for instance 'pick & pack,' where products were put into boxes according to the orders received, and then sent out to clients.

Nevertheless, in an analysis of the situation at the factory the distinction between upstairs and downstairs appears to be an important metaphor representing the class and educational differences between the two groups of employees. Most of my participants had left school at around the age of sixteen and were of working-class background. Working at a factory was probably aligned with the expectations they forged of themselves as part of their class belonging (cfr Willis 1993[1977]) and educational background.[33] Workers repeatedly presented office jobs as out of reach for them, but also as undesirable. One of them told me that his father, who was a manager, had always told him to remain at a lower level job, as that did not carry responsibility that would keep him awake at night. Another one told me:

> *I still love being active, I don't wanna be stuck behind a desk all day. I don't… I can't stand any… that sort of thing. I hate being, you know, being stuck*

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[33] See for instance Hakken 1980 on the role of different educational activities in the reproduction of working-class culture.

behind a desk, and doing desk work. I need to physically be moving around and doing stuff. That's why this job [at Spring] I could still do that at the moment.

Commenting on his level of acquaintance with the white-collar employees at Spring, the same worker said: 'I don't really know much the girls upstairs. I don't know who they are, what they do, apart from [name of one female employee].' Although it is true that most people upstairs are women, his reference to their gender suggests that desk jobs may be seen as less masculine than those on the shop floor. In anthropology it has been highlighted how constructing one's masculinity, or even hypermasculinity, may go hand in hand with forging one's persona in a particular professional domain (see for instance Menzies 2019 on fishing and Wacquant 1995 on boxing, cfr Sherouse 2016). More broadly, the ethos of machismo can be put into practice in some particular types of jobs, for instance in the transport sector (Bolton 1979:338-339). Although female workers were numerous on the shop floor, the quote above suggests that the work that took place there was conceived of by workers as more masculine than office work.

The ex-factory manager also pointed at the worker's background as a reason why they did not transition to clerical jobs. Although my question referred to visually impaired people generally, it was clear that his answer referred to visually impaired workers now employed on the shop floor.

Q: Why do you think there are not many visually impaired people applying for roles in the office?
A: I don't know, I think… I can't say why we don't get any external, but I think internal I think they just enjoy working on the production floor. Yeah. I think… Maybe they view it as… They wanna do a job and go home at the end of the day and not have any responsibilities to worry about, whereas I think some of them might associate office work with… It kind of have to take some of the work home with you. I don't mean physically, but I mean in your mind: 'I've got to do this, I've got to that, I've got to have this meeting.' I think the majority of them where they've been so factory based, they like that kind of environment, and they like the fact that it's 8.00 till 4.30 and I can go, leave it at 4.30 and

come back, and it will be exactly where I left it, the next day, and I haven't got
to worry about it.

This statement substantiates the fact that there are other factors at play besides disability, notably social class and level of education, which determine why visually impaired people do not transition to roles that may be considered better from a career advisor's perspective. As the ex-CEO phrased it, 'Maybe I think sometimes lack of ambition is seen as a negative, whereas it's a life choice that should be respected.' This helps to explain why the 'keeping busy' by performing repetitive tasks was not looked down upon by workers.

Bergstresser's ethnography is illuminating in this respect. She carried out fieldwork on a farm in Italy where people with mental disabilities were employed with the aim of making them feel part of society. In Italy one's identity is linked to one's profession (2006:12), so much so that 'professional identities […] can exist even in the absence of formal employment' (ibid:13). The unique contribution of Bergstresser's work to the present research is her analysis of the effects of employment history (related to social class and educational background) on the acceptability of a particular type of work programme for the disabled. Bergstresser observed that working on the farm was indeed therapeutic for people of a lower socio-educational background: their identity was strengthened by their job, which was also compatible 'with local concepts of real and honest labour in the agricultural and working-class' local area (ibid:15). However, those who had a university degree perceived their involvement in the farm as demeaning (ibid:17-18). Their identities were shattered, rather than reconstituted, by the work programme at the farm. Among workers at Spring there was no previously established intellectual identity to compromise. Besides, a good proportion of my participants had known little or no employment elsewhere, and therefore did not carry with them a professional identity that needed to be sustained. Workers did not feel stigmatised by the fact that they worked at the factory. They were, it is true, a non-representative sample: one of them told me that some visually impaired people despised 'workshops' and abhorred the idea of working in one of such institutions. For my participants, on the contrary, a job at Spring provided them with a sanctioned social position in the society where they belong, i.e. a role as employed people.

One person who, unlike most workers, did explicitly articulate the difference between upstairs and downstairs in terms of education was Amir. Born in Asia into a family of modest means, he was not sent to school until he later emigrated to Britain, at the age of 14. When I talked to him, he said he regretted this missed opportunity: 'If today I had one or two degrees, although I have [mentions his second disability] I could still have a support worker [and perform a job requiring a higher level of qualification]. But because I'm not educated, I'm not qualified to do certain jobs. And I think that was the reason why I'm in Spring.' He continued by saying:

> *If you are educated, believe me, you are a powerful person. Education is so important. If you've got lots of money, the more you spend it, the less it becomes. But people's knowledge, the more you spread it, the more it becomes. Education is very vital, very important, very powerful. People have lots of food at home, but the more you eat it, it becomes less. If you've got money in your bank, the more you spend it, it becomes less. But if you are educated, the more you spread your knowledge, the more you use it. If you have knowledge… I pass it on to you, you pass it on to someone else, it spreads. If you are not educated, your disability is gonna be more a problem to you, but if you are educated, you can come over that.*

Although Amir did not mention the 'upstairs people' in his comment, his words clearly expressed his belief that better qualified jobs can only be taken by people with better qualifications. Amir was perhaps one of the most ambitious workers, and he presented the broader consequences of lack of education for disabled people: 'If you are educated, no one can defeat you. They can defeat you physically, but they cannot discriminate against you.'

3.4.c Financial Considerations

One reason why workers at the factory, as well as those outside, needed their job was the financial remuneration they gained, which is the third factor that kept them at the factory. The paycheque was indeed featured among the reasons for being in employment mentioned by workers: 'Q: What's special about coming to work? A:

You get paid, you get to pay your bill, you go on holiday, you buy your food. Without money, how would you manage?' A worker defined his level of pay as 'just about liveable' and 'better than no wages,' and this was the general impression I received on the relatively few occasions when the topic of salary was brought up. In fact, in reference to his pay, another worker said that he had 'to claim benefits to match it up to make it work.' From my informal conversations with workers I could gather that most of them were single-person households, or the sole breadwinner of the family, or part of a low-income household. This made them quite dependent on their paycheque. Moreover, judging by their professional trajectories, most of them had spent a life on a low salary, or on no salary at all. One worker told me he had known better days in the past, when he was working two jobs and making £2000 per month. Although he presented this as good pay, taking into account the cost of living in Donchester this level of income would probably not guarantee him a high level of savings to fall back on.

Factory workers were aware that, given the tough job market, an alternative would be self-employment, but they never contemplated it, as it is characterised by volatile earnings. Another option they ruled out in favour of keeping their job at Spring were temporary jobs found through employment agencies, which are not stable. The 'permanently temporary' nature of today's world of work (Beck 2000[1999]:89), which Carrie Lane describes in regard to white-collar workers (2011), affects workers at the factory more seriously. Outside of the safe boundaries of the factory lies a world of 'part-time, short-term, usually contract positions, bridged by periods of unemployment, underemployment, and self-employment' (ibid:9). This world is even more daunting for blue-collar workers, who do not have the level of education to aspire to better-paid and more stable positions, and may also lack the skills to navigate a complex job-search process.

An alternative open to workers at the factory was to rely entirely on benefits, but they preferred the sense of dignity and self-worth that comes with being in employment. It may, again, be argued that my participants were a self-selecting sample in this respect, but some workers had actually experienced both being on benefits and being in employment. One of them commented on the former situation saying 'benefits made a whole mess of my life.' There was a sense that being on benefits

entailed being in a more passive position, and one that would lead to low levels of social engagement and poor mental wellbeing. Nevertheless, from the point of view of factory workers, working additional hours by doing extra work inside the factory or by finding a supplementary job outside the factory was not to be pursued at all costs, as they had to strike the right balance between salary and benefit payments. Ulrich Beck describes unemployed people as 'thirsty people who have to promise not to drink one drop of extra water, because they are officially given one glass a day to moisten their parched throat' (2000[1999]:90): in the 'brave new world of work' unemployed people are financially insecure, but cannot use their ample free time to earn more because their benefits would be cut or curtailed. Beck's analysis is applicable to my participants at the factory, for whom the trade-off between salary and benefits was crucial. The system is structured in such a way that sometimes it is financially counterproductive to take on more work hours or a better job. This is why the 'in work support' officers at the factory had to perform 'better-off calculations' in order to assess whether an employee would lose benefits when moving on to a position outside. For instance, it was not desirable for employees to find a better (for instance full-time) job outside if, all things considered (transport costs, etc.), it may have been more profitable to remain in the present position and complement one's income through benefits.

The above considerations shed light on the other side of the claim that work is much more than just a salary. This rhetoric is present in contemporary Britain, as it was in the Britain of the past (Phillips 2004:112), but financial considerations are still intrinsic in the choice of if and how much to work. How chronically ill people have responded to structural constraints is exemplified by Julia Segar's ethnography on epileptic patients' non-compliance with medical treatment: the positive effects of medications would jeopardise their chances of receiving disability benefits (1994). Spring workers' way of exerting control on their lives was subtler: they navigated the system so as to maintain their job without unduly compromising their financial position. No matter how vocal my participants were in regard to the Government's lack of implementation of the laws aimed at securing equal employment opportunities for visually impaired people, they did not elaborate on the more subtle political implications of the passivity experienced by those who are recipients of public hand-outs. Other ethnographic studies can, however, inform an analysis of

this situation. Jie Yang described the gifts bestowed by the Chinese Government on unemployed young workers (ranging from flour, to money, to the provision of low-rent housing) (Yang 2013:119). This unveils the covert control that can be exerted on the unemployed at a structural level. Just like gifts replace denied economic prosperity, are benefits a flawed way to replace genuine employment, the meaning of which goes beyond a mere salary? My informants would probably answer this question in the affirmative.

3.4.d Sociality

The main reason why workers treasured their work at the factory was indeed social. The importance for disabled people of the social aspect of the job has been documented elsewhere (Cotner et al. 2014:52), as has the importance of social networks for them to secure a job (Cotner et al. 2014). There were various facets to the sociality that was present at Spring. Firstly, the sense of sociality and camaraderie that pervaded the shop floor and that, incidentally, was also appreciated by workers in the old workshops (Phillips 2004:180), was much valued by workers at Spring. The weekly raffle and the Christmas dinner were scheduled opportunities for socialising, but the more pervasive daily banter was the real glue that bonded people together. As workers worked or sat in the canteen, they would shout to a colleague sitting not very far from them, or passing by, calling them by their nickname and jokingly saying things such as 'Are you behaving?' They would also quietly approach a visually impaired colleague and tap them on a shoulder, and then move away in the opposite direction.

As it is apparent from the ethnographic literature, shop-floor culture is characterized by different forms of resistance, which also function as a unifying force among the workers (see for instance Korczynski 2014:140-163). Camaraderie, which pervaded the shop floor at Spring, could have been an additional tool to subvert or resist the rules dictated from above. Interestingly, though, I only recorded one incident where banter was used as a weapon to assert the difference between upstairs and downstairs; here is the excerpt from my fieldnotes:

Today the CEO came in to tell us there were some people from a radio station that came to interview him and other staff members, and he mentioned that the crew would visit the shop floor. He kindly asked workers for permission to switch off the radio, as it may create copyright issues in case the radio crew wished to broadcast the recordings. A while after the radio had been switched off and no visitor had come to the shop floor, though, the line leader said something along the lines of 'We deserve our own camaraderie!' and turned the radio back on.

If camaraderie was not used as a subversive 'weapon of the weak' (Scott 1985), it was, however, used to highlight the commonality among shop floor staff: disabled people often joked about disability in a way that would not have been tolerated in mainstream society.

The second facet of sociality at Spring was the sense of safety and mutual understanding that workers often associated with the inside prong of the inside/outside distinction. Inside, health and safety was second nature. The shop floor, in spite of being equipped with machines, felt free of hazards. Outside, the need to put in place health and safety measures was, in the opinion of many of my participants, used as an excuse not to hire disabled people. Inside, people were understanding of people with disabilities; outside, they were not. For instance, a participant who also had a hearing impairment told me that the latter disability troubled her more than her visual impairment, and that she could 'not hear very well what they [people] said outside.' There was also a great sense of mutual trust at Spring and, conversely, I do not remember people expressing mistrust towards anybody. The following scene from my fieldwork illustrates this:

A staff member came to the shop floor to collect some money for a social event. The worker in a wheelchair sitting next to me, who does not have a high level of manual dexterity, had problems handling the coins he had received back as change. The cleaner, who was passing by, suggested going to the worker's locker and taking his bag, so that he could put the change directly into his wallet. This was all agreed without problems. The visually

impaired worker next to me commented: 'That's what I like about this place: you can trust people.'

The third way in which sociality at the factory manifested itself was the mutual enrichment that people derived from working alongside people that were different from them, whether in terms of type of disability or lifestyle and personality. 'You find out what they like, what their hobbies are, what they do at the weekend,' commented a worker. More importantly, workers could 'feed off each other regarding technology, or regarding things they might find difficult, or what is an accessible washing machine for a blind person, for instance.'

The social aspect, in all its manifestations, was essential to why workers had remained at Spring for years, sometimes even decades. As Graeber pointed out, most people do not spend their time in activities that we define as economic: plenty of time is spent in socialization (2001:68). This also explains why jobs at the factory did not fall into the category of the 'bullshit jobs' described by the same author. They were not 'completely pointless, unnecessary, or pernicious' (2018:9-10) and, in particular, it was definitely not the case that 'even the employee [could not] justify [their] existence' (ibid.). Not only did the employees testify their devotion to such jobs through their long journeys to work, but also the social aspect of the work could not be disentangled from the definition of the job. In fact, when I asked factory workers to tell me what they did at the factory, some of them presented social activities (e.g. organising the raffle) alongside work tasks. Ultimately, for what reasons did workers at Spring continue to work at the factory?

> *It's good to have a job obviously, it makes you feel worthy, makes you feel like you've got something to get up for in the morning. It makes you feel like you've got a purpose in life. When you get a wage at the end of the week, might not be very much, but it's something, isn't it, it makes you feel like you are not just sitting at home watching telly.*

This quote and the discussion presented above anticipate the importance for workers at Spring of adhering to a broader social narrative of employment. I will expand on this topic, as well as others, in the next chapter; now I will illustrate it with the portrait of Jim.

3.5 'See the Capability, Not the Disability': Portrait of Jim, (Now Retired) Factory Worker

If the actual work carried out by workers at Spring was not featured in their discussion as prominently as being in employment, what counted as work for them, in particular outside of the factory? I conclude this chapter with the portrait of Jim, a factory worker whom we meet here at his place shortly after retiring. As someone who managed to remain in employment almost continuously since he left school, he has a rich professional trajectory to relate. In his words emerge various themes dealt with in this chapter, and in the thesis as a whole, notably education of and by visually impaired people.

Jim was an active participant in my project and always made himself available to answer questions on his life as a visually impaired person in Britain. On this, he could offer a historical perspective: having experienced gradual sight loss since his youth, he had lived through many social and legislative transformations. He often enquired about my progress with my research, expressing a veiled concern about what I may do professionally after completing such a long-term programme of study. Brought up in a working-class home, he had never heard of the word 'PhD'; when I deciphered its meaning, he reacted with amusement and simply kept calling it 'your course.' His own curriculum being centred on practical skills, he believes that education must have a tangible purpose and be applied to work. In this portrait, we see him 'posing', like most distinguished sitters, with his *opus magnum*, i.e. the portfolio of his vocational achievements. However, we also see him as a busy family man, rolling up his sleeves no longer to make one more cardboard box, but to help his wife in the home and fellow visually impaired people through a local charitable organisation. As an old age pensioner, Jim has not forfeited his strong work ethics: in his life, care and work merge into each other, and he still has a lot of care to give, even after formal employment at the factory has, for him, come to an end.

'It's hard work. I come away, you know, proud I've done it!' Jim is talking to me about his work life. He mentions his portfolio, a folder he has compiled over the years

accumulating credentials about his professional experience and education. Jim was encouraged by his teacher to keep a record from the time he left school until he retired, so as to have something to pass on to his grandkids. Jim dutifully compiled the book, updating it with the help of his NVQ (national vocational qualification) tutors and, more recently, of the 'in-work support' officer at Spring. Nevertheless, when he takes it out for me, I realize that his daughter has never seen it. I ask him: 'Did you keep it secret?' 'No, I just put it upstairs, and forgot about it.' He was hoping, however, that it could inspire the workers who temporarily join Spring as part of a scheme supposed to launch them into a proper career.

Jim, who is 65 and lives with his wife on the outskirts of Donchester, has recently retired from the factory, where he worked for 21 years. 'It is all written down. I thought they could use this to help these people, who come in two days a week "Look at Jim, he's blind, look at what he's done! He's achieved it!"' He left the portfolio with the 'in-work support' officer at the factory, hoping that the employees for whom Spring should be a springboard to other professional opportunities would consult it. But as I flip through the pages, it becomes apparent that it has not been properly consulted for years. Some pages are kept safely in plastic sleeves. They have actually been glued to them by time, and when I pull some of them out I realise that the ink has left a mark on the plastic sleeves. The portfolio is a relatively thin A4-size book. Embossed on the leather cover are the gilded words: 'National Record of Achievement.' Each word is written on a separate line, and the margin of each line is slightly to the left of the one above. The impression that they form ascending steps is emphasized by an equally gilded line forming the shape of steps and framing the writing. Jim has carefully collected proofs of his educational and professional pathways over the years, and archived them in this portfolio in chronological order.

He talks me through his professional life history, as we sit on the sofa in the living room of his suburban home.

> *When I was born, I was visually impaired, I was classed as partially sighted. Back in the early '50s I went to normal schools, first junior school, and then I went to secondary modern school, even though I had difficulties reading the blackboard. I used to sit at the front of the class. Basically I muddled through.*

I left school when I was fifteen years old, and went out into the big wide world. I said to my Dad: 'Now I've left school, I need more pocket money.' He said: 'Well, there's the front door. Open it, and there is a big world out there, go find a job. That's part of life. You've left school now, go find a job and start working.'

Jim followed in the footsteps of his father. Like Jim, he had left school very young, at fourteen, and worked hard, doing sixteen-hour shifts when needed. He had also 'diversified' his career, which spanned over 50 years. Again like Jim, he had experienced the shock of being made redundant. Jim describes his own career:

I found my first job as a can lad,[34] working on a building site, making tea and coffee and helping the builders. I did that for about one year. All the time I was under an eye specialist, and after one year I went to work for a company that is part of the steel industry. I started there as a post boy, picking up post and delivering post to all the different departments, and then I got a job in the stores, and I was there for approximately a couple of years. I was still under the eye specialist. And then in 19… [thinks] must have been 198… [thinks], 1970 I was recommended by the eye specialist to go to a rehabilitation centre in [name of county], to do assessments, because my eye sight was going down. So I went there for a whole year, had various assessments and while we was there we did work experience in local factories. That's where I met my wife. Then we got married in August '73. Just after that, I went to another Government training college in [other county]. I did a six-month course in storekeeping there, and when I came back, I applied for another job and I got another job for a religious book company. I had to get used to ISBN, which is 'International Standard Book Number,' every book had an ISBN. I did that job for around 3 months. They kept promising 'You'll get a pay rise,' but it never happened, and then in my lunch hour, I got an extended lunch hour, and applied for another job at a company that dealt with TVs and videos and Hi-Fi systems. I started there in 1974; I worked in the stores, picking and getting orders together. And then I graduated to pack cathode-ray tubes. I used to

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[34] From 'billycan,' a metal pot with a handle used to boil and carry water.

pack them, all the different sizes. I did that for a number of years, and then due to the eye condition I went on to packing, and I completed eighteen years working for that company, and then got made redundant in December 1991. So I completed eighteen years… Working there all them years and then ended up redundant!

Here is a text that Jim typed as part of his training to get his NVQs, which followed his redundancy. It expresses his eagerness to fight on:

I was made redundant in December 1991 after seventeen years continuous service. I felt quite rejected as I thought I had a job for life.

I knew that to get back into work I had to diversity from general warehouse work because of my visibility [sic] problem.

I applied to [college name and location] and did a 9 week course, after which I applied to [college name an location] for a Telephony Business Administration course.

When I first started I thought: 'What the hell am I doing here!' after being out of education for so long. After a Foundation Course, which I looked upon as a settling in period, it didn't seem too bad.

In January 1994 I started on the main Telephony BA course. I found it hard going at first until I got into a routine. I think I held my own throughout the course, as I was in a group with students half my age.

I have gained a lot from the course, confidence, knowledge and abilities I did not know I had.

The main thing that has helped me through the past 3 years is my ability to adapt to any situation and just knuckle down and get on with it. As at the end of the day you only get out what you are willing to put into it which gives you the overall result.

When my course has finished I hope to put into practice all the knowledge I have gained over the past 3 years. If I do not it won't be for lack of trying.

Jim continues his story:

So when I got made redundant, I thought: 'It's gonna be hard to find another job.' So I thought: 'The only way to get back into work is to learn computers.' So I applied and went to a college, and did a residential course there for 3 months, to build up keyboard skills and general knowledge, and then I spent two years at another college, run by a sight-loss charity. I did a foundations course there, and came out of there with NVQ level 1 and 2 in business administration and telephony, and I also did a telephony placement for a bank. After completing the course I applied for jobs, in 1995 – 1996, and kept getting the same scenarios: 'Oh, you've got the qualifications, but you haven't got the experience.' It was like a catch 2 [sic] situation, you couldn't get one without the other. But I never got the opportunity and then, luckily enough, a place came up at BBM, as Spring was called in them days. That was on the 1st September 1997, and I worked there till the 11th October 2018. The job was funded by my local authority. This vacancy at BBM came out 'cause a lady was leaving. She was funded by my local authority, and through somebody I knew, they told me, and then I managed to get a grant transferred to me. So that's how it came about. This is what is called… networking between individual blind people. Because you find that a lot of things are advertised, like various benefits, different help organisations, but you don't find out about it, only through the blind network.

And when I first started here, I was working in basketry, started as a porter. Basically getting in the materials and giving it to the gentleman in the benches, so they could complete their work. Then a gentleman left, and a bench became available, so I did a course in basketry, did an NVQ level 1 and 2, and then for seven years I was making baskets, and everything to do with basket manufacturing, and then due to high costs of rental of the premises they had to shut that section down, and I had to move to the

confectionery side, which was another part to learn, you know, a new
challenge to learn a new job, and basically I was there approximately 21 years
and six weeks. And now [smiles] I'm being paid by the Government to stay at
home! I'm a pensioner now. As you can see, from all this relevant information,
I've had a varied career, even though I suffer from a visual impairment — my
sight gradually went down over the years — I managed to keep employed for
45 years! And the rest is history in the book.

From the school yard across the road the sound of children playing reaches us, as if to highlight how important education has been for Jim. He retraces his educational steps: 'Rehabilitation centre in 1970-71 for a year, then there was the college for six months, then there was the assessment centre, then the other college. Plus the NVQ working in basketry. There was quite a lot of education there.' In fact, when I ask him 'What are you most proud of, in your career?' his answer is:

Keeping employed for 45 years, and achieving a lot of things in education,
and NVQs. I've always adapted myself to different situations. I went back to
education nearly 30 years after completing my schooling, when I was nearly
40 years old. And then try to compete with young people [smiles], which was
quite nerve-wracking. And then the younger people were more 'Oh, I wanna
go out and enjoy myself,' whereas my attitude was: 'Well, I'm here, I've got to
make the best of what I've got. Do the education, get the qualifications, and
prove to myself that I can do it.' And I did it! I worked hard, and I played hard.

The list of courses listed in Jim's portfolio is long, and ranges from 'data processing' to 'processing petty cash and invoices,' from 'liaising with callers and colleagues' to 'health and safety,' from 'creating and maintaining business relationships to 'telecommunication and data transmission.' Although he left school at the age of 15, Jim is, in many respects, a learned man. In his professional life history, which he conveyed to me as a persuasive story, he highlighted how hard it was for him to go back into education at the age of 40, but also how proud he was of doing this. He pointed out that his professional trajectory was 'varied,' as he worked in different roles and in different sectors. He also knows the history of Spring, and the names and acronyms of the different benefit systems that have been put in place in Britain

throughout the last decades. He is a savvy citizen who regularly listens to the news, and even sets aside time to listen to the Chancellor of the Exchequer's budget speech live. Most of the words that recur in Jim's speech are related to learning and, conversely, showing and teaching. For instance, in regard to the fact that people with many different disabilities work at Spring, he highlights the strength that people can gain from simply seeing what workers with other types of difficulties can achieve. 'It says to the other disabled people: "If he can do it, I can do it", instead of having the defeatist idea "Oh, I can't do that, I can't manage that," without even trying.'

In spite of his determinedness, Jim can also get discouraged: 'I find life frustrating myself, sometimes. In the morning sometimes I wake up "Oh, how am I gonna face today." Sometimes you face a lot of ignorance, out in the world.' Jim has had to face ignorance, like many people with sight loss. He gives the example of standing at the bus stop and saying hello to the people he can hear around him. 'Sometimes you hear people, but they ignore you!' He attributes this to their ignorance: 'Maybe they don't know how to approach a disabled person. "How do I handle it? Do I speak to him?"' In spite of the adverse situation, Jim's willingness to learn has helped him stand up for himself: he is keen on educating key people in mainstream society, as well as other disabled people. He recalls taking an English course that was offered by the company to its employees years ago. He used the literacy skills he gained to type on the computer a letter to the manager of the train line he used to use. He complained about drivers not activating vocal announcements, making it difficult for people with a visual impairment, as well as other travellers (with dyslexia, learning difficulties, or simply a limited knowledge of English) to understand when to get off the train. His letter, which was checked by his tutor, received a response: drivers would be encouraged to switch on vocal announcements at the beginning of their journey. This made Jim quite pleased.

Jim thinks education could play an important role also at the national level. When I asked Jim what could help people change their attitude towards disability, especially in employment, his answer was: 'education.' Talking about the Remploy 'workshops,' which were shut down in an attempt to integrate disabled people into mainstream workplaces, he told me:

The Government should have said: 'We are shutting them down, but we should be out there educating the employers,' you know like, I can't give instances now, big companies out there. They should be educating them. The Government should be educating outside employers that you see the disability, but look beyond it. See the capability, not the disability, and as I said, since I've been here, we have people come and go on the Work Choice programme. My attitude is: you see the person for what they are, not what their disability is.'

In Jim's opinion, what should be done in practice is:

to recruit some disabled people to actually go in and talk to employers. All right, I'm a blind person, but give me a job and I'll show you what I can do! Don't look at me as disabled, look beyond it. All right, you have an eyesight problem, but you can do different things!

Like various visually impaired people I have spoken to, Jim has actively volunteered to educate sighted people, in particular staff at his local authority, about visual impairment. Using a popular method, he blindfolded half of the sighted group and asked the other half to guide them. The former had to eat, count money, and complete other mundane tasks without using their eyesight, while the latter had to get used to helping people who were (in this case, only temporarily) without sight. In the exercise, the two groups then swapped roles, giving everyone a chance to experience both situations. Jim says the attendees found the exercise 'frightening and interesting,' and understood that the belief that blind people have a particularly sensitive hearing is an 'old fallacy.'

It is interesting to notice that, while Jim has educated sighted individuals about visually impaired people, he has also learnt the proper ways of behaving in the sighted world. He remembers going for a mock interview when attending a training college. The other interviewees were a gentleman of his age, and two eighteen-year-olds. He was appalled to realise that the latter were dressed in jeans and trainers:

If you've got an interview you've got to sit up straight, face the person, you've got to dress appropriately, you know, shirt and tie, depending on the type of interview it is, and you've got to know something about the company you are going to the interview for. It goes on first impressions. If you turn up scruffily dressed, not showing much interest, or not knowing anything about the company…

Considering how keen he is to both learn and teach other people, Jim was quite disappointed to realise no one had consulted the portfolio he had lent to the 'in-work support' officer at Spring. He thinks people, in particular people of a younger generation, didn't bother to consul it: 'Some people's attitudes is: "I can't do it", that's it, dismiss it.' Jim says: 'I thought the portfolio would be a nice thing to show people: "Now look at this particular person, what he has achieved over the years". Don't forget a lot of them people coming here are in their 20s, they've still got 40 years ahead of them. They are just contented with coming in two days a week, and that's it.' He counters this by saying: 'If you are willing to learn, you'll do it.' He describes being taught how to make a box out of a flatpack, and then making it in different ways, until he found his own method, which he then taught to others. 'They are teaching me, but then I end up teaching somebody else.' About his professional life, he says: 'It was hard work, but I achieved what I wanted to achieve. Now I always say to people here: "'All right, you've got your various problems, the same as everybody else, but if you put your mind to it, you can achieve anything. Don't let your disability hold you back." It shows if you are determined enough you can do it!'

More than through his book, however, Jim has inspired fellow workers at the factory with his example and, I am sure, also many other people he has met on his personal and professional journey. I am curious to know what job he enjoyed the most:

All the jobs I've done over the years, I've enjoyed. But my best achievement was learning basketry. Even though I've got the eyesight problem, it was a great achievement for me, it made me feel proud, that I've achieved it [laughs]. To look at a basket, you think: 'How do you make that?' but I managed to do it, with a lot of help and guidance. But it just shows you that if you are determined enough, you'll do it.

Jim is proud of his work, but equally proud of his personal achievements: 'I left school at fifteen, but I've achieved a lot in my life. And I've been married 45 years, I've got two grown-up daughters and four grandkids. I've done something right! [smiles] And I've managed to buy my own house, which is another achievement.' Jim and his wife still use the baskets that Jim made at the factory, baskets that epitomises the fruitful effort that Jim puts into everything he does. Besides, Jim is careful with money, and he is proud that his children 'never went without anything' when they were growing up.

Just as Jim's dedication goes beyond the professional sphere, so does his 'work' not limit itself to the factory. As in the case of many people with sight loss, a lot of 'work' goes into his daily life. Jim's wife is visually impaired herself and suffers from other complex medical conditions. Both receive great help from their two children, one of whom is employed by the local authority as their part-time carer. Here is Jim talking to me about his daily routine, before he retired:

> *I get up at 4.30 and then my wife gets up. I make sure she has a drink and cereal, make sure she has her medication, and then I do different things, like putting the drying away from the night before, and doing various things. So by the time I've completed all I do is near enough time to come to work. Now I'm leaving later because of minicabs [Jim's guide dog was temporarily out of service because of an operation], but usually I leave home at twenty past six to get the bus. Four-thirty–six-thirty: two hours, just flies by, because I'm doing various things.*

His day after coming back from work was not leisurely either.

> *At 4.30 pm normally I leave Spring and go to the bus stop, wait with Stella, my guide dog, and whoever is there, and get the first bus, get off, wait for the second bus, and then that drops me near enough across the road from where I live. And when I get in, I start work again [laughs]. Sorting Stella out, making sure she gets her dinner, get her fresh water, then anything the wife wants doing, then have a shower, then sit down have my dinner, then at 7.00 give*

the wife her medication, then relax for an hour or so, then she has her other medication before she goes to bed, make her another hot drink, let Stella out in case she wants to do anything; by the time you twitch around it is time for bed! [smiles] I am working before I get to work, and I am working when I get home, and the weekends doing washing and that.

It is unsurprising to know that Jim, who is so active, took part in various social activities before retiring:

Then we decided in my local area — about six of us decided: 'Well, here we haven't got a group for visually impaired people, run by visually impaired people.' Most organisations, the people who represent that particular disability are able-bodied. They don't suffer with the condition that they are represented, so we decided: 'It would be better to have a visually impaired group, run by the visually impaired': they can understand different issues, and relate, but we do have sighted volunteers to help. And we set up this group over twenty years ago, and now it is still going strong. When I retire, it will give me more time to be more involved with the group. We could get more things done, in conjunction with social services.

Speaking to Jim now, after his retirement, he tells me about what has kept him busy: 'I'm doing pottery, then I'll be trying the shooting range, then I am hoping to do a bit of computers, and then I am hoping to do bowls! And that will take four days out of seven! [smiles].' Jim is not going to add these activities to his portfolio, though, which is purely on employment. He joked with Spring's manager once about going back to the factory to make up boxes, which he was very good at doing, but in practice he would not like to go back to work, as he would need to pay too much tax on his salary.

Nevertheless, his job is engrained in his internal clock. Even three months after retirement, this is 'still daunting, really, 'cause you still wake up at the same time. Wake up at 4.00 o'clock! It takes a long time to get out of the system, gradually getting used to this, not working.' His guide dog retired from its role shortly after Jim retired from the factory. She seems to have had a smoother transition into this new

phase of life, as she is now 'enjoying her retirement in the countryside, and chasing different furry animals around, like rabbits and squirrels.'

Chapter 4. The Pros and Cons of Narrative among Workers at Spring

4.1 Introduction

This chapter analyses the emplotment that occurred among workers at the factory. The sense of community, sociality and job security workers felt at Spring, which was introduced in chapter 3, was ever present in their narratives. Although these narratives took different forms, they were all pervaded by the importance of professional work, and especially of a job at Spring, for their lives. In this, their emplotment proved to be strongly embedded in its particular cultural context: I argue that, in spite of being in non-mainstream employment, workers developed stories that resonated with master narratives on the importance of employment that pervade British society, and Donchester in particular. I also contend that workers' narratives were not entirely therapeutic insofar as workers conceptualised Spring as the only organisation where they could be employed, leading them to fear for their future. Moreover, I show how workers, in the spirit of the craftsman conceptualised by Richard Sennett, endeavoured to project a positive image of people with disabilities through their professional engagement, and through the social involvement that came with it. The desire to leverage even the most quotidian aspects of one's life to change people's perception of disability was an important commonality between workers at Spring and all my other participants. I conclude the chapter with policy recommendations for a world of employment that also includes supported workplaces like Spring, and with some insights that Spring offers on the future of work.

4.2 'Narratives of Competence' and 'Overcoming Narratives' in a Comfort Zone

As I outlined in chapter 3, sociality was an important reason why workers said to treasure their job at Spring. Moreover, the feeling of 'kinship' among visually impaired people, which I described in chapter 2, was palpable at the factory: the

sense of community workers found on the shop floor was due to the camaraderie of the shop floor environment, as well as to their common condition as people with disabilities. This discourse on community dovetailed with the one on the security of their work environment: workers conceptualised Spring as a protected, caring and welcoming place. In this regard, I found a remarkable affinity between Spring and a completely different ethnographic context: Bethany, the Indian leper colony presented by James Staples (2014). The difference in cultural and socio-political context between Britain and India, which would merit a detailed analysis but is outside of the remit of this thesis, seemed almost to emphasise the similarity between the lived experiences of these two communities. Almost the antipode of the Spring shopfloor both geographically and culturally, the Bethany community seemed to resemble it in two domains that are important for the purpose of this discussion, i.e. attitude to work and means of subsistence, and community belonging. Lepers there did not wish to leave their colony for mainstream society, in spite of Government and NGO community-based rehabilitation programmes trying to make them employable. The way lepers described the boundary between the colony and the world outside was strikingly similar to the way Spring factory workers described the difference between the company where they worked as part of a supported employment scheme and mainstream employment. The sense of safety that members of the leper colony and Spring workers felt was due not only to camaraderie, but also to the financial gains they received as part of a sheltered environment. What gave lepers dignity was not work per se, which they could find in mainstream society through income-generation programmes, but the monetary retribution that came from it, which was higher for those working informally as beggars (Staples 2010:79). For factory workers the more likely alternatives of a job at the factory would be self-employment, which is characterised by volatile earnings, or temporary jobs found through employment agencies, which are notoriously precarious (cfr Purser 2019). These more precarious forms of making ends meet would compound, in their view, with a more alienating and less tolerant workplace, which is why they kept their jobs at Spring.

Shop floor staff were aware of the special attention they received at the factory, in fact some of them recognised that Spring was, in many respects 'a comfort zone' vis-à-vis other workplaces. Firstly, this organisation adapted work tasks and work rhythm

to workers' individual strengths and weaknesses more than a mainstream employer would be willing to do. Not being able to operate a tape gun did not make a worker unemployable: it simply meant that the company knew he had to be given the time to learn this very basic skill. Secondly, workers received special assistance in domains that were not work-related. Ed, who had worked in mainstream employment, told me how privileged workers at Spring were, in his opinion. 'The welfare side, they bend over backwards' he said, thinking back to when his boiler broke and he had to rush home, and he was still paid for the day. Ed was particularly aware of how sheltered Spring was from the fast-paced rhythm and harsh conditions of the mainstream working-class jobs that he had experienced. The following passage, in which he describes his job as a builder, makes a counterpoint to the humane nature of the shop floor at Spring that I have been describing.

> *I was in there for about three and a half years, four years, so while I was in there, he [employer] also had another building site, he had builders in there. So I used to do overtime at night in there. So we finished work at five pm and then go on working there till midnight or two or three in the morning, whatever. So I liked it so much in there [the building site where he worked at night], I wanted to get a job in that building, so I was in there full time, and I worked for the company for I think twelve years in total [at all three building sites combined]. It involved weekend work and stuff [describes his main tasks]. Whilst I was at [the third and his favourite site] obviously the overtime was incredible. There was a lot, a lot of overtime, so we were doing maybe 100–120 hours a week. So we'd finish, say, three or four in the morning, go and obviously get a couple of hours sleep and go back to work at five in the morning. So this is what screwed my head up, 'cause now I can't sleep very well. You don't know that at the time, you are just doing the overtime because you wanna earn the money, and obviously I had a family, so they needed money, and our wage was so low, 'cause they knew this, we were paid so crap money we had to do the overtime to make that money up. I managed to become a foreman. So I was in charge, during the week, of eight people, during the weekend I could be in charge of up to forty people.*

Workers who, unlike Ed, had only worked in sheltered businesses also realised that working in mainstream employment would be more taxing. 'In the sighted place I guess they want more from you,' told me one of these workers, who said that in a job 'outside' visually impaired employees would have to 'keep up with sighted people.' The sense of comfort that Spring provided to its workers even extended to bodily care: the company subsidised part of the costs of a pedicure, whereas the rest was covered by the relevant worker.

The management of Spring was also conscious of the sense of security the company offered to their workforce. For instance, the new CEO explicitly called the support that the company informally provided to its employees 'extra wrap.' Helping workers to sort out their council-tax bills, or booking their hospital appointment, or even going with them to meetings or appointments were all part of this extra assistance offered to them. This informal support seemed to create a bond between shop floor staff and some long-standing employees, notably the factory manager. She had helped them for years without resenting the extra time and effort she had to put in: 'I've spent more time with these guys than with my family! [laughs],' she commented.

It should be noted that some forms of comfort are provided to employees also by mainstream companies, past and present. The provision of facilities aimed at the wellbeing of the workforce is characteristic of some early industrial developments in Britain (Owen 1966), and a discussion on healthy workplaces is also alive in today's society (see Stringer 2016). In lamenting a clear-cut separation between Spring and mainstream companies my participants referred not so much to various perks that come with the job, but to the accommodation of people with disabilities, as well as the openness to hire them in the first place. In the type of fulfilment they derived from their jobs, their position was similar to that of the Serbian factory workers among whom Rajković did fieldwork, who were wedged between the security of a job where they did not have much to do and the threat of losing their job, between 'the comfort of being subsidised and the threat of an imminent closure' (2017:54). In order not to compromise their economic stability, they engaged in what Rajković calls 'mock-labour,' which did not require their creativity at all. Like them (ibid:61), workers found comfort more in spending time on the shop floor than in the actual productive capacity they exercised there, which dwindled or sometimes even stagnated

depending on the demand for production at a particular moment. Again like the workers at the Serbian firm (ibid:48), my informants thought there was not a lot that Spring could do but, unlike them, they were more outspoken about what 'the Government' could have done better to help people with disabilities get jobs. These considerations are an important backdrop to the stories shared by workers at Spring, as they compel us to focus on what mattered to the workers themselves: being in employment as opposed to being on benefits, but also as opposed to the actual labour that such employment required or, at the quietest times, not required of them. Because many of them had found insurmountable difficulties in securing or retaining a job before coming to Spring, being hired by this company was an important feature of their narratives.

Worker's narratives all included the theme of the community spirit and safety they felt at Spring, but they took different forms. Broadly speaking, they could be subsumed under the categories of 'narrative of competence' or 'overcoming narratives' (Bloom 2019:123). Sometimes, as in the case of Jim's story, they could be defined as both narratives of competence and overcoming narratives. I borrow these concepts from linguistic anthropologist Molly Bloom, who deployed them in her autoethnography of female wheelchair basketball players. 'Overcoming narratives' are characterised by a turning point (ibid:129), just like 'redemption narratives.' The latter term has a religious connotation that the former does not possess, and most of my participants' stories were formulated in a secular vein. Nevertheless, they had a strong focus on self-transformation, and that is why I use the terms 'overcoming narratives' and 'redemption narratives' interchangeably. A redemption narrative is defined by Dan McAdams as a story 'about people moving from suffering to an enhanced state or situation' (2006). McAdams studied this trope as a quintessentially American phenomenon (ibid.), but I would argue that this sense of transformation can also be found in my ethnographic setting. The stories my informants created resonated with cultural values permeating Donchester, such as the importance of employment and independence, and in particular with stories circulated by the media or by charitable organisations about the potential for success and resilience of people with disabilities. The discourse around the 2012 Paralympics is a case in point (see Davies 2012, Powell & Myers 2017). Visually impaired people may be both the recipients and the producers of such stories, which are co-constructed at a higher

cultural level as well as at the more quotidian level, of which I attempt to give a fine-grained description in this thesis.

The overcoming narrative was present in the stories of my participants at Spring. In fact, one of the things that struck me about the way workers related their professional journey was that they always remembered the exact day when they joined the organisation. This turning point changed their lives, professional and otherwise, and was therefore still affecting them on a daily basis. One worker even recollected the whole chain of fortuitous events that had led him to secure a job at the company:

> *I was still trying to find a job. I went to the Job Centre in [location], I went to six different job advisors. 'Cause I only stayed in the job for about three months, then move on so I get a new one. This was getting on for months and months, and I was getting sick of it. In the end this woman in [location] Job Centre, who was disabled herself in a wheelchair, she heard about my case, she wanted to help me, 'cause she felt sorry for me 'cause I had been trying and trying. So I went to [that Job Centre], which wasn't in my area, but they said: 'Well, we'll do this as a one off' and obviously they got this leaflet from this factory. She told me to come. She said 'Are you interested in factory work?' 'Not really, it doesn't appeal to me, but we'll have a look.' So she drove me there one Friday, I was invited to the one at [Spring's old location] to have a look around. We went there Friday afternoon, there was no one there, just the management was there. I had a look around. 'Are you interested?' 'Well, I'll give it a go.' Then they said 'Come down, the following week, when obviously people are here, and we'll give you a trial on different things.' And that's how it started, but I was out of work for seven years.*

In spite of the importance of overcoming narratives for some workers, however, I found that, overall, narratives of competence were more present among Spring workers. The overcoming narrative, thanks to its turning point that gives it a novel-like structure, may be more appealing as a way to inspire others. However, workers at Spring proved that narratives of competence can also be apposite tools to change people's perception of disability. Just like the basketball players (Bloom 2019:123),

they thought their disability did not prevent them from integrating into society, and in particular it did not prevent them from doing so through employment. At the same time, also like basketball players (ibid.), they thought that their impairment could be leveraged in order to fight the stigma attached to disability. A parallel can be drawn between adaptive athletics and supported employment: just like the athletes studied by Bloom 'linguistically construct themselves as non-liminal in narratives' (ibid:121), the fact that the workers' employment was supported did not prevent them from seeing the social value of what they did (see ibid:128). More importantly, it did not prevent them from representing themselves as living 'full lives' (ibid:132). Workers at Spring were aware of their rare position as employees of a supported business, as well as of the shrinking room for non-mainstream employment in Donchester. Just because of that, they treasured the opportunity given to them by the organisation 'to participate fully in socially valued aspects of life' (ibid:122) and, more importantly, to use such opportunity in order to project a more positive image of disabled people.

An example of narrative of competence is the professional history that Amir, whom I introduced in the previous chapter, proudly shared with me:

> *That was the question in my interview, in my first job. 'What is your weakness?' I said: 'My weakness is me being blind.' 'So what's your strength?' I said: 'That is also my strength, me being blind.' My blindness is my weakness, my blindness is also my strength. And I said: 'Me being blind, that is my weakness, because that's the reality. But my strength is that, despite me being blind, despite that I can't see, I wanna work.'*

Amir then recounted with enthusiasm the thrill of being in his first job, where he had both to answer between 50 and 100 phone calls a day in his desk-based role, and also go and run eight or nine errands a day all around Donchester, using public transport. Amir then went on to work two jobs at the same time: a factory-based one from Monday to Friday, and one in another industry on Friday night and during the weekend. He did so because, as the eldest son, he felt the obligation to support his family in his home country. There, he thought, life was much harsher, but so was life for all disabled people, anywhere:

It's a tough world out there. If you go out, nobody is gonna lay flowers for you because you are blind. You have to adjust yourself. And for someone like us, it's not gonna be easy, nobody is gonna feel sorry for you. It's not easy, but you have to force yourself, you have to show to them that 'I'm good.' If you are not gonna show to them, nobody is gonna say to you: 'Are you good?' Or: 'You are good.' You have to show to them.

The effort to use one's story to effect a positive transformation in others, whether employers or other individuals who surrounded them in different capacities, was a thread linking most of my informants. This will be at the heart of chapter 6 of the thesis.

4.3 The Porous Border between 'Inside' and 'Outside': Culturally Embedded Emplotment

After focussing on the narratives produced by the workers, I would like to develop the notion of the cultural situatedness of stories, which I introduced in the previous section. This notion pertains to all stories, also those that my other research participants crafted as a way out of the crisis of sight loss (cfr McAdams 2006). Anthropologists have studied therapeutic emplotment as a phenomenon that is culturally embedded (Calabrese 2013). Indeed, the literature that highlights the importance of mobilising the cultural imagery and symbols of patients in order to heal them is seminal to anthropology (Lévi-Strauss 1963:186-205, see also Dow 1986). Even when people do not see themselves as fully personifying the established cultural norms, they articulate their marginal position vis-à-vis the dominant life narrative (Kavedžija 2019b:140). Sometimes, a master narrative is profoundly tied to the socio-economic context where it develops. When, following a socio-economic crisis, the adherence of people's stories to this master narrative is no longer attainable, individuals may develop alternative narratives, based on different values (Jefferson 2013:105-106). At other times, master narratives can be so powerful as to influence personal narratives even after societal, historical and political changes have given rise to a world that is at odds with such master narratives (Van de Mieroop & Pagnaer 2013).

A small qualitative study of therapeutic emplotment such as the present research can inform a broader ethnographic understanding of a society because individuals select and modify stories that are available in their particular context (McAdams 2006, see also Frank 1995:75), and because 'self and culture come to terms with each other through narrative' (McAdams 2006). McAdams's research centres around the influence of the cultural context on the narrative patterns we develop. For instance, the redemptive narrative that is so present in America could only have developed in a society that gives so much importance to individualism and independence (ibid.). Donchester society is considered, even in comparison to other parts of the country, particularly individualistic. Although the infrastructure, notably transport, is superior to that of other cities in England, and in spite of the high number of charitable organisations, the provision of assistance on a more personal, humane level, is seen as more difficult to obtain. This results in a lot of pressure for people to be independent. Considering that work is an enabler of independence (financial and otherwise), it is not surprising to see work take a prime position in the lives and narratives of most of my participants, particularly those at Spring. In both their overcoming narratives and in the narratives of competence, work played a crucial role.

As I discussed in the previous chapter, a job was treasured because it guaranteed much more than a financial gain, which could also be bestowed by the benefit systems, but with more dire social and psychological consequences. Different anthropologists have studied the perceived value of various forms of retribution. For instance, in her analysis of the different forms of economic support used by her informants with mental illness, Sue Estroff showed that they were ranked differently (1985:118-173) and she argued that, although benefits were accepted by some of her participants, they ultimately contributed to their lingering in a marginal social and professional position (ibid:165). Also apposite is Clara Devlieger's ethnography. In regard to *documentaires*, beggars who issue certificates to donors in order to present themselves under a more respectable light, she noted: 'People view certain types of dependencies as more dignified and moral than others' (2018a:4). Unsurprisingly given the cultural context, Spring workers regarded fully depending on benefits as more demeaning than being in paid employment. As Devlieger argued,

'Begging was the opposite of "work:" degrading, making a person entirely reliant on the labor of others, while with "work" a person had dignity in being notionally independent' (ibid:10). Spring workers rated a job at the factory as higher than being on benefits even if such employment was not gained in the competitive job market. Conversely, just as lack of work in other ethnographic contexts has been equated with disability and being physically disempowered (Joshi 2009:333), Spring workers equated their disability with dim professional prospects outside of the confines of Spring.

Situated in a society that values work as a mark of identity and where work is an important motor of sociality, workers at Spring treasured their job at this company primarily because of the opportunity it gave them to perform the 'work' of being active as meaningful social agents. The work of filling, packing and labelling I described in the previous chapter was ancillary to the social function of work. Workers seemed to be happy *in* their job at Spring rather than *of* their job (see Grint 1998:28). It could be argued that, as a non-mainstream workplace, Spring could be regarded as the polar opposite to social integration. After all, it derived from a 19th century blind workshop, a type of institution that acquired a negative connotation because of the segregation of its workforce. It could also be argued that my informants were a self-selected group. In fact, the workers themselves told me that some of their fellow visually impaired people would not contemplate taking a job at Spring, as they considered it below them. However, Spring workers were clear in their expression of the social belonging that was enabled by being in employment. In sum, work was a pillar of the 'full life,' to use Bloom's words (2019:132), that they aspired to live.

It is important to remember the cultural embeddedness of the workers and of the narratives they created. Although the boundaries of the factory differentiated it in some respects from mainstream employment, they were also porous enough for workers to be aware of the values that underpin life and work 'outside.' In other words, the walls of the factory were permeable in that they allowed social values to filter into the shop floor. Besides, the fact that the sociable atmosphere was among the most important reasons why workers came to work does not mean that they didn't have a social life outside of the factory. Family members and friends, with or

without sight loss, were the most obvious providers of social contact for my informants, but volunteers and support workers were also part of their social circle. With all of these people, workers engaged in different leisure pursuits, such as shopping, cooking, listening to music and to the radio, going to the theatre, travelling, exercising and, in spite of the negative connotation that 'sitting at home watching telly' had as a metaphor for being on benefits, also watching television. The socialization happening for these workers outside of the factory did not negate the importance of the factory as a social space. If anything, many of my informants, just like many of the blind poor described by Phillips, craved for independence and respectability gained *through employment,* which are important norms of society 'outside' (2004:112). This emphasized the role that socialization *at the workplace* had among my participants, as well as British people as a whole.

I have until now focussed on the positive influence that narrativization had on worker's otherwise quite challenging lives. At this point it is perhaps unsettling but legitimate to wonder whether some of Estroff's findings may be applicable to Spring workers. To what degree did those whose salaries were complemented by benefits feel entitled to, rather than demeaned by, this form of extra financial support (cfr Estroff 1985:154)? To what extent was their perceived difficulty in securing a job outside due to an interiorization of a social label that equates disability with reduced productivity (cfr ibid:167)? Could the hostility of the outside world they described be partly explained by a selective memory biased towards negative life experiences, or again by a partial recounting of them? After all, oblivion can be an integral part of narrative at both a personal and a collective level (see Littlewood 2009 in regard to the latter) and, although I have emphasised the entanglement of life as lived and life as narrated, sometimes there may be no narrative at all about aspects of people's lives that are actually prominent in their daily living (Garro & Mattingly 2000:25). Answering the above questions is complicated by the individuality of the workers' personal and professional histories, as well as values and believes. What I can argue with confidence, however, is that my participants at Spring were not 'paying lip service to the work ethic' (Estroff 1985:127): they were genuinely attached to work, and in this regard they were firmly culturally embedded in their context. However, they were set apart from mainstream society, which advocates a roll-out of integration into mainstream workplaces in the name of equality. Workers actually

supported sheltered workplaces like Spring, as well as positive discrimination policies. I will lay the foundations for the reasons behind workers' stance presently, and return to their own solutions to the issue of employment for people with disabilities towards the end of the chapter.

Workers at Spring reiterated the fact that the divide between inside and outside, which was at the centre of their discussions on integration, was actually constructed by the 'outside' world itself. An illustrative story was Bob's failed job application. He had been told by the recruiter over the phone that he was qualified for the job. However, when he submitted his application, in which he disclosed his visual impairment, he was told he did not fulfil the requirements for the position, in spite of ten years of relevant experience. This discouraged him from continuing his job search. Just as workers blamed mainstream employers for the low employability of disabled people in the world outside, so did they seem to suggest that disability was a category created by the able-bodied:

> *We don't expect if it was in an outside factory, we wouldn't expect it to be treated different, you know, we are still a person same as everybody else. It's just we've got a disability, but it's not a problem to ours, it's a problem to you, you know. You see it as a problem, we don't. You still pay your bills, you still go shopping, you still have relationships with other people.*

In sum, Spring workers regarded the world outside as having a negative influence on their professional and personal lives all while borrowing from overarching narratives available in their cultural context in order to craft their own narratives. With these narratives, which took different forms, they tried to exert some influence on the same mainstream world that marginalised them, and tried to show the capabilities of disabled people. If the narratives Spring workers formulated were culturally embedded insofar as they espoused the importance of work that permeates mainstream society in Donchester, what else made not only *their* narratives, but all of my participants', specific to Britain? This is where a comparative approach is most germane, as the literature on disability in other contexts can help give a negative definition of cultural specificity in the British cultural narratives. A point of interest is the role of the family in the lives of people with disabilities. As Priestley pointed out

(1995), visually impaired Asians in Britain felt that sight loss organisations in this country did not give enough space to their families. My fieldwork provides evidence that this is the case. Although friends and family were welcome to attend the classes organised by Sunshine, generally speaking the services provided to blind and partially sighted people in Donchester were tailored to the individual. In contrast to this, in the Global South, these services are normally provided by a network of kins even within the formal space of the hospital (see Addlakha 2020:S49 on India). Many of my informants praised the support they had received from their families, but this social entity was seen more as an enabler of independence than as an entity in which they were embedded. This was in line with the culture of individualism present in England described in the academic literature (paragraph 2.6) and portrayed in bestselling books (Fox 2014[2004]).

Besides the family, the state is an actor vis-à-vis which narratives are shaped differently in different cultural contexts. In various countries and in different historical periods, states have legitimised some forms of disablement and elevated some types of people with disabilities above others. A notable example are injured veterans, who have enjoyed privileges in comparison to other disabled people. This has given rise to a feeling of entitlement vis-à-vis the state whenever it failed to provide to people injured in conflict the recognition that they felt they deserved. For instance, in the early 2000s, Turkish amputees who had been maimed fighting for their country in the mid-1990s felt that they were owed a (financial and moral) repayment of their (physical and moral) debt from the state, which had not paid for their prosthetic limbs, thus pushing them into financial hardship (Açıksöz 2020). In my research, the state (or, rather, 'the Government') featured prominently in the factory workers' conversations as a 'disabler' of professional chances for visually impaired people. On the contrary, in my middle-class participants' discourse it was overshadowed by the role played by society's attitudes in preventing visually impaired people from achieving their full potential.

Just as the roles of the family and the state influenced my visually impaired participants on a personal, rather than merely intellectual, level, so did other aspects of life in Britain. For instance, Jim was proud of the fact that, in spite of the challenges that he had encountered as a visually impaired worker, he had managed

to purchase his own home (paragraph 3.5). In so doing, he had realised a dream of home ownership that is not specific to Britain, but that in Britain is particularly indicative of one's neoliberal aspirations (McRuer 2018:189). Another contribution to the present discussion comes from those of my informants who had been brought up in Asia: they were well-positioned to highlight aspects of their life in the UK that were, if not specifically British, then at least different from their home countries. As we will see in the portrait of Yussef, while they lamented the apathy they sometimes experienced in Britain, they were also saddened by the sympathy that they received in their native lands. They were particularly concerned about explanatory models of blindness that attribute the cause of sight loss to the sins committed in a previous life by the person affected by sight loss or her family. In the narratives that my participants shared with me, the absence of such explanations was in itself a trait that characterised them. In the following section, I return to the importance of work in the shopfloor staff's narratives and show how their emplotment was not entirely therapeutic.

4.4 'Sitting at Home Doing Nothing': When Emplotment Is Not Therapeutic

Since offering 'meaningful employment' to people with disabilities was the ethos of Spring, I was curious to discover what 'meaningful employment' meant for my informants. Here are a few definitions given by the workers:

> *Meaningful is… employment! [laughs] You can have your own money, do whatever you want, whereas… trying to find a job is just… impossible, if you've got a disability. Well, not impossible, very hard. Just having a job, being employed.*

> *It means you are in a job and you are doing something that you like to do, with other people. Not just sitting around doing nothing. You are in an environment and you are being positive, using your brain.*

Well, employment that you take part in, employment that matters. I mean, it's not good doing something that don't count for anything. It's meaningful employment, we actually produce something, and to me that's what meaningful employment is. Not good doing something that doesn't count for anything.

Just having a job, gives you self-respect, you are not sitting at home, you've got a purpose in life, you are working for your money, instead of just sitting at home, they [the company] are giving you a chance to have a job, other people won't give you a chance. You stay at home, what's the Government gonna do? 50 pounds a week? Or something like that? Not really much, really.

It's good to have a job, obviously, it makes you feel worthy, makes you feel like you've got something to get up for in the morning. It makes you feel like you've got a purpose in life. When you get a wage-packet at the end of the week, might not be very much, but it's something, isn't it; it makes you feel like you are not just sitting at home watching telly.

These quotes reveal that, in the discourse of the workers, meaningful employment meant having a job in the first place. I came across other clues that this was the case. For instance, some workers were confused about under what programme they were employed, i.e. whether their salary was paid through Work Choice, a local authority grant, another scheme, or the company itself. A worker even speculated that his salary, or a portion of it, might be paid by the central Government. There was a sense that, as long as they got paid, they were not concerned about where the money came from. This may have been due more to fear of 'messing up' the fragile system of benefit payments and salary than to disinterest. Crucially, far from elaborating on what could make a job become more meaningful, workers' precarious employment situation led them to juxtapose having a job at Spring not to a different, perhaps better job, but to having no job at all.

Unemployment, or 'sitting at home doing nothing,' loomed large in workers' minds, and it is apposite at this stage to problematise the power that emplotment has to heal. The literature on the benefits of narrative is vast, but so is the one on its

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failures. As it has been pointed out, we can become prisoners of our own stories (Freeman 2014:86) and become engrossed in clinically counter-productive narratives that hinder recovery (Shohet 2007). Coherence in one's life narrative is normally positive, but when it consists of a string of losses, it is perceived as 'the weight of a destiny that comes to freeze the movement of [one's] life' (Vanthuyne 2003:420). Moreover, individuals can also be unable to break away from the culturally embeddedness that makes stories powerful both in a liberating and in a suffocating way. For instance, Iza Kavedžija shows how the stories of 'salaryman' and 'housewife' present in contemporary Japan may orient men and women, respectively, in their life choices, but may also feel to them like a pattern to which they have to conform (2019b:90). Another example is Winskell et al.'s study of young people's written fictional stories on HIV: it reveals that these young writers had absorbed local cultural assumptions that blamed women and practices not conforming to Christian doctrines (2013:209). Besides, the stories they invented were far from therapeutic: most of them ended in death or with a tragic diagnosis, without envisaging a fulfilling future for the HIV-positive character (ibid:202). In other cases, the solace offered by narrative may prevent patients from seeking more profound political changes (see Miles 2009:10). Finally, in situations of socio-economic disparity between interlocutors, narratives produced in order to read the mind of the other may lead to mutual misunderstanding (Mattingly 2008).

My ethnography at Spring adds one voice to this chorus describing the failure of narrative. As I listened to the workers' concerns, I came to realise that the same narrative that portrayed Spring as a haven of understanding and openness to people with disabilities was a double-edged sword. To workers at Spring, 'outside' was rife not even with uncertain professional prospects but with the certainty of unemployment. Therefore, the safety with which they associated Spring was illusory: in reality, just the fact that this company was seen as the only possible employer made it a source of apprehension. If inside was safe, outside was not full of opportunities, or even challenges, but a guarantee of nothingness. Although this thesis brings attention to the benefits of work for people with a visual impairment, and also to the power of narrative to help them reshape their lives in the face of a medical crisis, narratives may fail to be therapeutic. The narratives of workers at Spring are a case in point: in singling out the factory as an island of tolerance and

safety, workers also portrayed the mainstream world of work as totally closed to them. It is true that these visually impaired workers were quite confident that a person with their disability could 'do pretty much whatever [they] put [their] mind to, with some support.' However, when they were asked about themselves, they became much more economical with their dreams. This led them to feel dejected, which in turn had repercussions on their life choices.

> *If I lose my job in the next three or four years, I will pretend to job search or whatever, but I'm not gonna struggle. I'm being honest, I'm not gonna struggle. Why? What's the point?*

Bill told me he had started to mentally prepare for early retirement by scaling down the number of hours he worked, instead of planning to look for a job in the event that Spring shut its doors.

> *What's the point? I would know how to start a job search, I roughly know how to do a CV, though I'm not very good at writing, I know what's required. But… are they gonna take me on with my age, my disability?*

Bill then presented the case of a person working in the downstairs office at Spring who, in spite of her dedication, had not enjoyed a remarkable career: 'She's fantastic,' he remarked, 'but she's here.' In sum, from the comments above the workers appeared, to use Rajković's term (2017:56), 'demoralised', i.e. they felt their own striving to live up to the value of work was constricted by factors beyond their control. In this regard, it is apposite to remember that, in his analysis of Spring, the ex-CEO had pinpointed the lack of role models as a negative influence on the workers. Workers who developed skills that allowed them to secure a job outside disappeared from the shop floor and from Spring. Visually impaired workers who already possessed those skills, as well as IT skills, never came to Spring in the first place, but worked for the whole duration of their career in mainstream businesses. In the ex-CEO's opinion, this lack of role models had repercussions on the way shop floor staff could envisage their future professional trajectories.

In sum, it was as if all the years workers had spent at the factory, or at similar organisations, had prevented them from taking a closer look at the multifarious range of professional activities in the world of outside employment, and at the various skills needed to perform such activities. In turn, this had affected their capacity to identify the skills they had, those they did not have but could develop, and those they would never possess. This is an excerpt from an interview with a worker:

Q: What skills could you use… Could you use any of your skills, any of the skills you have to do another type of job…

Q:… in another company / A [interrupts Q]: If I wanna leave what, if leaving here?!

Q: For example, yeah.

A: No, I don't think so. I have never thought of that.

Q: Have you ever thought of that?

A: No.

Q: Why is that?

A: I've never come across it really, I have never thought of that. What to do outside here. Because I think I've been here too long, that's the problem, you see. I have never thought of that. If I left here, what I could do in my own area? This was a problem in [old municipality where he used to live]. I asked my social worker and my doctor. My doctor said: 'There are no jobs in the area.'

Q: That was back in the… what years?

A: 2000.

The following is a typical answer that I received when I asked workers about their most valuable talent.

Q: What do you think is the best talent you have to offer to an employer?

A: Best talent? Oh, gosh. What, skills, or…?

Q: Yes.

A: I'm not too sure, to be honest.

Q: It can be a personal skill, it doesn't have to be something too technical or academic.

A: I'm good at dates.

The worker then went on to ask me my date of birth, and with complete nonchalance stated correctly that it was on a Wednesday. When prompted to think of any applicability that this skill might have, he admitted that it had none for his present job, and that he could not think of any utility that this skill may have in other jobs. Other workers I interviewed were also at a loss for how to answer my question on their best talent, and only after I had pushed them further did they offer answers such as 'just get on with stuff, try and get on with things,' or 'I don't know. I'm a good communicator, I suppose. I like humour. I'm a good socializer.' When I asked them what their dream job was, they were equally puzzled: 'I mean, I've done this kind of things for it would be 30 years this year, if we hadn't been made redundant. I don't really know!' told me one of my participants.

Anthropologist Eleonor Antelius's study on the narratives created by personnel in a day centre for people with acquired brain damage (2007) resonates with the atmosphere on the shop floor at Spring. Just as the incurable condition of the patients led their health-care practitioners to focus their narratives on the present at the expense of hope for the future, my participants' aspirations were curtailed by their belief that the world of mainstream employment was not open to them. Shop floor staff at Spring did not dream of a career, the 'ladder of social biography' (Hassard 2000:30) in today's society. Their attitude went therefore against the grain of a social context where professional stability is often equated with weakness (Sennett 2006:41). Although their social network, at least for some of them, spanned wider than the confines of the factory, the restricted range of work tasks and professional environments they had known did limit the range of pathways that they considered as potentially open to them. As the CEO of the factory, whom I quoted in chapter 3, pointed out, the shop floor culture is not one of cultivating professional ascent. If a career is 'the definer *par excellence* of the individual's progress in organised society' (Hassard 2000:29), workers at Spring demonstrated that lack of progress within an organisation does not prevent some individuals from carving out a role for themselves in society. Still, what can be observed is that workers were not in a position to choose or not to choose to pursue various professional aspirations. They were rather in a situation where they were not fully aware of options that may

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be within reach for them in the first place. Their conviction was that, if they were to leave Spring, they would be out of work.

Workers' concern that Spring may go out of business, it must be said, was not unjustified:[35] given the closure of all the other 'workshops' in Donchester, the future of Spring itself was very uncertain. For workers, this meant that this organisation was seen as 'the last resort' in terms of employment options. The new CEO had disclosed to all workers in a meeting the financial difficulties the company was facing, and the figures he had quoted were repeated by the workers on the shop floor as a token of how badly things were going. The sense of insecurity about one's professional life was perhaps more acute among middle-aged workers, who were too old to see themselves competing on the open job market, but at the same time too young to start thinking about retirement. Given the financial problems that Spring was going through, the scenario of 'sitting at home doing nothing' loomed large in everybody's mind:

> *Q: But if this place were to close down, what would your options be?*
> *A: I don't know, 'cause I've been in this kind of employment for so long, I suppose in a modern… It was something we all found when the last place [other 'workshop'] shut: none of us had the skills for a modern workplace! Cause everybody there was 30 years plus, so no one had what you would think of as the right skills to get a job today.*

The financial precarity of the factory was compounded with the workers' failing sight. Some workers' growing health problems actually went beyond their ophthalmological condition and in some cases were exacerbated by a lifetime spent doing manual labour. This explains why also people like Ed, who did have experience working outside, could not envisage themselves going back to the less protective world of mainstream employment. Since they saw Spring as the sole employer that could accommodate to their needs in this regard, they felt more dependent on this particular organisation.

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[35] While I was writing up the present thesis, the company went into administration.

In sum, it appears that the workers' worries were twofold. They were concern that Spring may shut down, which was not implausible. They were also convinced that, if that happened, they would be out of work. In my view, the workers' inability to see themselves working in an outside environment was also due to the work practices at Spring. Here I take the opportunity to offer a mild critique of this organisation. The same routine that reassured workers also seemed to paralyse their imagination. I would argue that emplotment requires freedom of action, as this can spur the imagination required to situate oneself in a more welcoming present and to project oneself into a more purposeful future. Such freedom of action was quite limited at Spring, where, for example, workers were assigned tasks, rather than choosing them on their own initiative.[36] Although it may be argued that such lack of initiative characterises working class jobs in general, where people do not get to choose their daily tasks (Roberts 2011:24), it is interesting to notice that some organisations providing work for people with disabilities have made of the freedom they give their workforce a part of their mission.

For instance, it is apposite to draw a comparison between the Fountain House model and Spring, as the ethos of the former gives a few insights into the freedom of action that, I contend, could nurture therapeutic emplotment at the latter. On the one hand, there are similarities between the Fountain House model and Spring. Both are aimed at purposeful employment for people with disabilities (Doyle, Lanoil & Dudek 2013:50), and organise the workday around a schedule (ibid:30, 32, 44). Furthermore, both wish their 'members' / workers, to transition to mainstream employment (ibid:35). Besides, the Fountain House offers formal help with non-work-related issues, such as housing (ibid:39), which the factory also does, albeit on an informal basis. In terms of social activities, Fountain House members enjoy leisure opportunities outside of work hours (ibid:31), while at the factory events such as the raffle and the Christmas dinner punctuate the week and the year, respectively. At a broader level, both organisations consider themselves as a social enterprise (ibid:49) and aim to change society's perspective on people with disabilities (ibid.).

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[36] As I was leaving the field, the new CEO was implementing measures to change this.

On the other hand, though, of the three tenets of the Fountain House model (fulfilling the 'need to be needed,' giving members freedom of choice in their work, and creating collaborative, non-hierarchical relationships between members and employees at all levels (ibid:54)), Spring only shared the first one. It fared less well in terms of collaboration between workers and staff at all levels, and in particular in the choice that its workforce could exercise while carrying out their respective jobs (ibid.). With regard to the first point, i.e. collaboration among staff at all levels, it is true that at the factory there was an affable relationship between line leaders and workers, some office staff and workers (in spite of the upstairs/downstairs divide), as well as among workers themselves. Still, unlike the Fountain House (ibid:58), Spring did not intrinsically rely on collaboration on equal terms, and workers or shop floor staff were hierarchically subordinate to office staff. With regard to the second point, i.e. the freedom of choice given to workers, I could not sense the factory 'empower[ing] its members to take responsibility for their own progress and that of others,' as the Fountain House did (ibid:XXIII). It appeared that the workers could exercise freedom in domains that were ancillary to work, whereas work itself was structured so that tasks were assigned, and each worker did not take as much initiative as the employees at Fountain House. The main attitude was one of acceptance, for instance of workload and of assignation of work tasks. 'Sometimes you get jobs come, sometimes you get jobs don't come, it all depends,' someone said to me. Or: 'I just do what I'm told.' The onus was on line leaders to identify who could do a job that needed doing at that particular moment, and call that person into action with sentences like: 'I'm gonna give you something to do.' This passivity may be the reason why, especially in the case of long-standing employees, which made up the majority of my research sample, immobility was more palpable than a desire to improve, or to transition to mainstream employment.

From this comparison it appears that Spring did not foster a spirit of initiative among workers. This, in turn, gave workers few prompts to imagine themselves doing something different, and doing something different elsewhere. Narrative may enhance visually impaired people's successes and use them as the backbone of therapeutic emplotment, of which I give many instances throughout the thesis. However, it can also stifle their capacity for imagination and the life choices that such

capacity may give rise to. Tropes can be repeated so many times that they may end up being — mistakenly — regarded as truth.

It is interesting to notice, however, that the picture of passivity that may emerge from my analysis of work practices at Spring and of workers' narratives is countered by the reality of what workers had actually done when they had found themselves out of work.[37] In other words, delving deeper into the workers' personal stories I discovered instances of activities that had occupied them when they were out of work because of unemployment or redundancy. Far from being 'sitting at home doing nothing,' they had engaged in pursuits that were not only meaningful per se, but also useful in view of securing a paid job:

Q: You mentioned that unfortunately you were made redundant as well…

A: Last year.

Q: Tell me about it.

A: Well, [charity name] got taken over by [another charity name], and I don't know why, they just decided not to keep running the place where I was working.

Q: Right, right. How surprised were you about this?

A: When [charity name] took us over we weren't very surprised, there wasn't many of us left. I think we went from about… [thinks] 100 of us, then we dropped to 60 people, then to 30. That was when they shut the factory in [municipal district], and then there was about eight of us left. So when it came… we pretty much knew we were on borrowed time.

Q: Right, right. When you were redundant, what did you do?

A: I met someone I hadn't seen since I was in school. And he was out of work, but he did lots of this kind of voluntary work, and it was on the run up to Christmas. He said 'There's lots of things happening, why don't you come?' That was part of [local charity], that was quite good: because there was everyone's Christmas parties, then there was this bowls things. I went to that, I just started helping out there. It's not something I'd like to spend my life doing, because, one thing, you wanna make some money, yeah, of course,

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[37] Cfr Howe 1990:215–216 on the unemployed.

but it's just a… was a useful thing to do, but… somehow not that fulfilling
somehow. Just a day here and there, maybe a couple of days a week.

This comment was substantiated by more remarks I elicited from my informants, asking what they would do if they were out of work, or indeed what they had done when they had been out of work. This is an excerpt from an interview with a worker 'Q: You wouldn't be sitting at home doing nothing. A: No! I would be busy out and about! I can't be sitting there watching TV.' A worker on a sixteen-hour contract told me he volunteered at a local sight-loss charity: 'You don't make anything there, but it's helping people, it's actually doing something useful.' Another told me: 'I was home for seven years, but not sitting doing nothing, just not getting paid for it.' In other words, he was keeping busy with various non-remunerated activities. Again another: 'I couldn't sit at home. I'm 59 now, this year, but it's not me. When I wasn't [in work] I was doing voluntary work. Different types of voluntary work, just keep me occupied, something to do. 'Cause I do get restless. Like yesterday I was at home, it was a nice day, and I went out for a walk.'

In her ethnography of aging Japan, Kavedžija highlighted how the elderly, by being providers as well as recipients of care, defied the notion of old age as a phase in life characterised by passivity (2015a). In their involvement as volunteers, some of the workers at Spring challenged the stereotype of both disability and unemployment as passive conditions. However, by using narratives in which they pictured themselves as 'saved' by a job at the factory, workers were unable to draw on their own, or their colleagues', broader life experiences to envision themselves in a different work environment, let alone in a more senior role. Their therapeutic emplotment was undoubtedly successful: they had found meaning in their lives, and their job played a big role in this, as it allowed them to feel they were active social agents. However, as it is clear in the pessimism they expressed in regard to their professional chances, in some instances their emplotment stopped short of helping them to strive for different, if not better, horizons.

4.5 The Craft of Changing People's Perception of Disability

One way in which workers emplotted their work at the factory as positive was that, by being employed at Spring, they felt in a position to improve the public's perception of disability. Having a job, no matter how apparently repetitive or uncreative, was, as I said before, beneficial to them on a personal level, as it made them feel integrated and included. I will now show how they also felt that they could change people's image of disability by working at Spring, as well as by performing the more general 'work' that being in employment and being active social agents required (in terms of mobility, etc.).

The effort put into changing people's perception of disability through work has been documented by anthropologists elsewhere. For instance, Meghan Ference described the fight of Kenyan minibus taxis (*matatu*) drivers against the stigma attached to their profession (2016). As they have the reputation of being reckless, *matatu* drivers can be shunned by potential spouses or even refused housing (ibid:105) and emergency medical care (ibid:109). Despise towards *matatu* drivers is expressed overtly, unlike the covert way in which people with sight loss in my context are rejected in the professional sphere. However, like in the case of Spring workers, the stigma affecting their professional facet is so strong that its repercussions spread beyond the professional domain. In order to counter this stigma, *matatu* drivers rely on unionization (ibid:107-110) and on providing better customer care (ibid:107). What brings together my ethnography and Ference's is the wish to alter people's perception of a specific category of people through the practice of a particular profession. Work was an important means by which workers at Spring, as well as all of my participants, foregrounded their capability over their disability.

It may be thought that workers at Spring, given their position in a non-mainstream company, were invisible to mainstream society. Like remote workers, invisible to their colleagues at the office, they may be regarded as 'seen-not-seen' (Strawn 2008:90, see also Jordan 2008:49-51). Nevertheless, they felt that their job put them in a position to participate in society in a way that may still be conducive to changing people's attitudes towards disabled people. The sense of self that workers at any company create may be constructed in spite of the constraints posed by the workplace (see Hull 2001), and I argue that it may also be constructed in spite of the social assumption that equates non-competitive employment with failure. In fact, the

voices of Spring workers, coming from an organisation that may be regarded as singular and even secluded, counter such assumptions in the same way as the narratives of the forgotten patients at a Brazilian hospice spoke of and to the social abandonment caused by that particular society and state (Biehl 2005:21). Moreover, my participants at Spring were the mirror image of the people with mental illness described by Robert Edgerton: whereas the latter endeavoured to deny their stigma (1971[1967]:145), the former put a great effort into performing and articulating their capabilities.

I would argue that the effort put into changing people's perception of disability is also 'work.' Indeed, it featured prominently among the different types of 'work' that all of my participants performed (from the work of negotiating one's distance to the VI community (chapter 2) to the work of organising their daily lives, to the work in the strictest sense of the term, i.e. employment). Furthermore, it was a type of 'work' that at Spring was performed at an institutional level, not only at a personal level. Although Spring was not a lobbying organisation, it was keen on opening its doors to various stakeholders and the media. On a regular basis, a small group of visitors, often dressed in business suits and accompanied by some of the 'upstairs' staff, would walk down the aisles of the shop floor and inspect the production process, sometimes stopping to chat with some of the workers. During our interviews, the latter would express mixed comments on these visits: some felt embarrassed by being looked at by strangers, others were neutral, and some expressed the hope that this form of promotion may increase sales, improve the image of the organisation, and ultimately help to keep Spring operating, in spite of its financial difficulties. Some workers even got involved in projects to promote the organisation and its ethos. For instance, they agreed to be featured in documentaries, which were shot either on location or on other premises. This allowed them to share their stories, thus uniting their own desire to inspire others with the company's wish to be recognised for its social efforts.

Some workers' desire to inspire others had, or at least had had, a more militant overtone. The focus of this thesis is on narrative, and the shop floor at Spring was rich in overcoming narratives, narratives of competence, as well as counter-productive narratives of a safe but precarious inside and a bleak potential future

outside. It is nevertheless important that, in my analysis, these narratives do not obfuscate the effort that workers had put into fighting for their rights in the political arena. Some of them had participated in demonstrations, contacted their MPs, or been active in a union in order to make their voices heard on topics ranging from the benefit system to the private sale of fireworks. My impression was that these struggles were more a thing of the past, in fact workers did not bring up these incidents unless prompted. Frankie, however, recalled one of these fights with pride:

> I took part in a demonstration to save disabled people's jobs. The council wanted to take away the grants of ten people in our company. We got together lots of disabled people through the union, and got them to demonstrate. We were outside the town hall shouting 'Save our jobs, you bastards! Keep our jobs!' We had the flags of the [name of disability organisation]. We then went into the town hall, where I gave a two–three-minute speech. I was the only one to talk; I still have the recording. It was in the newspaper the next day. I was in such an emotional turmoil. My father had fallen ill the day before, but instead of going to hospital to see him, I went out and did the politics. So that people never said I didn't try. When I was walking to the demonstration, I was crying. The day after the demonstration I went to see him in hospital. Those were not nice times.

The moment that to me as a researcher came to signify this wish to transform others, however, was much more humble. It was Jim's last day at Spring, which I describe in the following vignette. By bidding farewell to a workplace which, alongside many others, had given him the opportunity of being active professionally and socially, he marked the end of a working life that had been a source of both struggle and pride. His portrait (chapter 3) presented a narrative that was both 'overcoming' and 'of competence.' In this excerpt from my fieldnotes relating to his last day at the factory before retirement I show how, by taking leave from each and every member of the shop-floor staff, from old employees to new ones, Jim tried to use his life to convey the message that, with effort, things can become possible. With each handshake, he filled the gap between the implausibility of better work chances that had become part of the workers' bleak narratives and the tangible examples that countered those

narratives. Each goodbye was not a closure, but an opening towards the multifarious opportunities that he had embraced, and that he hoped others would embrace, too.

During the break, as Jim and I were having lunch sitting opposite each other in the canteen, there was an announcement, and everyone was asked to stay in the canteen after 1.30 pm. Before then, all the workers had gathered there, as well as staff from 'upstairs.' The new head of HR gave a brief talk, followed by two employees who recalled some amusing incidents from Jim's career. Then Jim himself went to the end of the canteen where the talks had been given. He took his guide dog by the lead, who would also be retiring with him, after six months of 'overtime.' He energetically patted the dog, while the dog equally energetically tried to go back to the other end of the canteen, as if heading for the exit. Jim's short speech contained good wishes for 'all the Seetec people,' that they may find their own way. As this went on, cupcakes bought by Jim were passed around. He had told me he had bought over 70 from Tesco, because he thought it would be better to buy too many than too few. I took one, and munched as I listened and looked around at people's reactions. Overall, no tears were shed, but it was definitely an emotional moment for everyone at the company, and one that extended well beyond this meeting.

In fact, at 3.00 pm (one and a half hours before the end of the day), Jim said he would go out and have a cigarette and then would go around to say goodbye to everybody. I asked if I could join him. We went along the factory lines, Jim asking me who was there, so that he could say a brief goodbye to each worker. The conversation was a mixture of camaraderie and jokes about retirement on the part of the workers, and sincere good wishes for the future of employees on the part of Jim. I was struck that he addressed these wishes both to young employees on a temporary contract and permanent staff who had been there for decades, as if they had a professional future ahead. Maybe I should not have been surprised, however, as Jim has always wanted to present his life as an example of how it is possible to do things, as if the 'knowledge by acquaintance' that he embodied were more powerful than the mere 'knowledge by description' (Russell 1910-1911) of the different

possibilities open to people with disabilities. 'I worked hard, I played hard,' he usually says. There were handshakes, pats on the shoulder.

As we went around, I felt immensely grateful and proud to be witnessing this moment. It was low-key, yet epic. As Jim shook hands with each single employee, I felt he also presented himself as an example to all the other employees. In fact, one of the most significant topics of the conversation I had had with Jim during my months at the factory was his desire to set an example, to show that if you want — and you must want it, because 'it is a tough world out there' — you can do it. He told me again the story of when he was made redundant in his early 40s, and decided to learn computers to increase his professional chances. The young people in his class lacked motivation and were just happy to be away from home, so eventually the teacher concentrated on him. Over twenty years on, of which 21 spent at the company, Jim looks back at his past with pride: 'I left school at 15, but I've achieved a lot in my life. I've got a good family and I've managed to buy my own house, which is another achievement [laughs]. Back in the early '80s, the price was down, a lot cheaper than they are now. But it was just fortunate that through hard work, I managed to do it, and determination.'

By moving on to retirement, Jim was entering a new phase in his life, a phase that would allow him to take some rest from professional work while continuing the 'work' of taking care of his family routine. He would also, as we learnt in chapter 3, sign up for different courses in order to keep active. The resilience and initiative that characterises Jim also characterises the participants I introduce in the following chapter, who had to find a new order in their lives after, and beyond, sight loss.

Like these other participants, Spring workers were craftsmen rather than masters in Richard Sennett's definition. Apart from those few who took part in formal initiatives to fight stigma, most of them tried to change people's perception of disability by concentrating on their work, as well as on the multifarious 'work' activities (being mobile, etc.) needed in order to live in today's society. Their engagement in this unassuming endeavour perhaps goes unnoticed to those who define non-mainstream workplaces as 'ghettos' (O'Hara 2017). Such critics also overlook the

historical trajectory that led both to the establishment of these institutions and to people with disabilities joining these organisations. These individuals' vocational histories do not run in parallel to the development of the legislation on employment opportunities for people with disabilities in the UK. Changes at the level of legislation are not translated immediately into practice, nor are they transferred seamlessly into the personal lives of these individuals, so much so that some shop floor staff at Spring mocked the DDA (Disability Discrimination Act) by reading this acronym as 'Doesn't Do Anything.' In so doing, they contrasted the idea that anti-discrimination legislation can have a positive impact on disabled people's life by bringing about concrete policies and changes in people's mentality (see Enyart 2020 on the Americans with Disabilities Act). Although I argued that workers' narrative can be counterproductive, I do not wish this to eclipse structural factors or the unwillingness of mainstream employers to hire visually impaired people. This was apparent in the vocational stories that all of my participants, at Spring and beyond, regardless of their walk of life, shared with me. Whereas the phasing out of sheltered employment is noble in its intent and can be a viable policy if implemented in the long term, the abrupt closure of non-mainstream workplaces is only likely to lead those made redundant to unemployment, especially those who have spent their entire working life in sheltered workplaces. In other words, the idea that sheltered workshops are obsolete in today's British society should not overshadow the fact that in a society that is not (yet) truly inclusive, supported businesses contribute to providing a diversity of workplace options. This is essential considering that a level playing field for disabled people in the labour market is far from being achieved.

4.6 Lessons from the Shop Floor

The lack of fair access to employment for disabled people, which emerges throughout my thesis and in particular in this chapter and the previous one, runs the risks of being overlooked by the general population. The unemployment rate in the UK is much more frequently circulated in the media than the unemployment rate for people with disabilities. Estroff observes that the percentage of disabled people in employment is used as an index of social adjustment because it is objective, and also because work is held in the highest esteem in our society (1985:121). If that is

the case, the fact that only one out of four registered blind and partially sighted people or working age in the country is in paid employment is a concerning statistic, and one that a good proportion of the general public seems not to be aware of. Unequal access to employment in Britain may also be masked by conjunctural and geographical factors. In regard to the former, during my fieldwork the country was going through a period of particularly low unemployment. Still, conversations like the following one, presented in an excerpt from my fieldnotes, were happening in the canteen at Spring:

> *'It is hard to find another job,' says one worker. 'It is a rough world out there, it is tough,' replies the other. As I start thinking of the fact that 'The unemployment rate in the UK was unchanged at 4 percent in the three months to August 2018, the lowest since 1975 and matching market expectations,' (Trading Economics n.d.), I am surprised by the dialogue I have just overheard, until one of them completes the sentence: '…for disabled people'. 'I have tried it myself,' replies the other.*

In regard to the geographical setting, firstly Donchester's unemployment rate is generally in line with that of the UK, and secondly Britain is associated with fairness and equality. These values may betray a more complex, and perhaps bleaker reality. Workers themselves were cognizant of this, as Amir pathetically expressed:

> *Look, this is Britain, right? No, I rephrase that: this is <u>Great</u> Britain. It's not only 'Britain,' it's a 'Great' Britain, right? And this Britain goes around and talks about human rights. I don't want to get into politics. Goes around and talks about democracy, and human rights and everything. If you really care about talking about human rights, there's millions of disabled people in this country, and only 8% of them are in employment. We are not talking about Nigeria, we are not talking about India, China, Syria. We are talking about England here, UK. Things should be different here. We go around the world, and we give this message that we believe in democracy, believe in equal rights… You couldn't even sort out the gender payment in this country, how are you gonna sort out people with disabilities?*

Amir's words shed light on the importance of looking at what may be concealed by an apparently low unemployment figure. But what were workers' solutions to the problem of the lack of employability of people with disabilities? The majority of them thought that the Government should encourage mainstream companies to hire people with disabilities by setting aside a proportion of jobs for them. The figures that workers proposed differed ('at least 20%,' 'up to 10%,' 'if a company employs over 100 people, one in 100 should be disabled, something like that'), but positive discrimination was by far the favourite policy of my participants at Spring, alongside some state subsidies to financially support workers in mainstream employment, at least during the initial phases of a job. Workers also thought that this strategy should go hand in hand with education: training workers, for instance in IT, on the one hand, and raising the awareness of mainstream employers on the other. They had faith that, given the opportunity to see what disabled people could do, employers would become more inclined to hire them. From a financial perspective, workers thought cash would be better spent in wages rather than in benefits. Some workers thought that the wages of people with disabilities should be funded by the Government, which should take 'the burden off companies' also in case the disabled employee had an accident at work. Another policy that, unsurprisingly, had the support of staff members of all levels at Spring was keeping workplaces like it open, and actually fostering the creation of more supported businesses. These are the words of Charlie, who had never had a job at a mainstream organisation:

> *Some blind people are in sheltered employment because they wouldn't cope outside, and I don't think I would. I don't think I would cope out there, in what you call 'open industry.' Some partially sighted and blind people might, but personally I don't think I would.*

All in all, workers' suggestions to solve the low employment rate of disabled people were against the grain in a society shunning sheltered workplaces and affirmative action. Here it is apposite to return to Estroff's ethnography. Although her informants, unlike Spring workers, loathed workshops (1985:139) and my ethnographic material presents some discrepancies with hers, I do subscribe to the overall message of her work. She unveils the contradictions of a socio-economic and political system that, while despising dependency, it fosters it among people with mental illness: 'the

professionalization of patienthood and craziness contributed to the client's ability to make it through life as a crazy person' (ibid:172). In other words: 'their *disabilities* function as do others' *abilities,* that their *incompetence* reaps for them what others' *competence* earns' (ibid:119, original emphases). In Estroff's analysis, people with mental illness are rewarded for their 'making craziness,' i.e. for being ensnared in their role as mentally ill person and remaining in a perpetual state of social and economic dependency (ibid:168, 172). Likewise, the lack of mobility of Spring workers speaks to structural causes of socio-economic dependence. Estroff focusses on the limits imposed on the personal and professional lives of her informants by society's stigmatization of mental illness (ibid:188-189). Likewise, after having explored the inside of Spring, I cannot help but pointing out the constraints imposed by the world outside, not only outside employers, but the whole socio-economic and political system. At first counterintuitively, these constraints consist in opening up the boundaries of Spring, and of the other few sheltered workplaces remaining, in order for their employees to merge with the mainstream workforce. With Estroff (ibid:186-187), I propose to listen instead to the people in question, and understand whether or not they want to be integrated. I by far do not auspicate a world where people with disabilities are set apart from mainstream society or workplaces. However, I do invite interested parties to listen to the voices of people like Charlie and consider sheltered workplaces as an additional, valuable occupational opportunity.

A study of Spring sheds light also on an even broader issue than the rights of disabled people to employment. As I write these concluding remarks, the world is experiencing an unprecedented medical and social emergency because of the Covid-19 pandemic. The current restrictions negatively affect visually impaired people's lives at multiple levels, but the present situation also offers a chance to discuss the nexus between the topics presented in this thesis and wider societal issues. For instance, although it is true that visually impaired people appreciate the fact that they have a job also because this gives them the opportunity of getting out of the house, it is also true that working from home may open up professional opportunities to those people with sight impairment who feel that going to work is as hard as work in itself. They may be able to avoid 'the second shift' (Hochschild A. R. & Machung A. 2012) of the daily commute, and literally sit at home actually doing

something (cfr chapter 4). Moreover, if some scholars have seen capitalism and the idea of the modern, productive worker as the culture from which stigma emerged and developed (Grinker 2020:56), then I speculate that work may be the arena where stigma is also dispelled. In fact, in the case of other disabilities, the workplace has been described as a place where socially denigrated people can be valorised (ibid:57).

This discussion falls within a broader debate on the future of work that started well before the pandemic. In his book published in 2020, Daniel Susskind argues that in, the present era, technology and automation will lead to a world were paid work is scant for everybody, not just disabled people. Therefore, how time is allocated will change, and ultimately the meaning of each of the (increasingly unpaid) activities to which we devote ourselves will change (ibid.). According to Susskind, the present historical conjuncture is unprecedented insofar as technology will not simply displace humans to alternative jobs, but largely replace them (ibid.). In other words, he argues that it should not be assumed that the growth happening thanks to the advance of technology will be supported by humans, rather than by technology itself. He believes that the task encroachment of technology into the domain of human capacities (manual, intellectual, and even affective) will result in less remunerated work available to people (ibid.). Susskind's analysis adds a layer of significance to my ethnography of the factory: it is not merely the description of a time-capsule, of an (almost) secluded environment living on from the times of Victorian blind workshops. Rather, it is a microcosm of the world (not just the world of work, but the world *tout court*) that may well be. This supports Ginsburg & Rapp's idea that 'disability worlds […] offer a crucial diagnostic on the future that confronts us all' (2020). In this respect, I have tried to offer a few insights by showing the meaningfulness that workers at Spring attribute to their jobs.

Susskind also observes that some schools of thought consider work as intrinsically meaningful, whereas others warn that the purported meaningfulness of work actually distracts the subject from the pursuit of meaning in other domains (2020). In this latter sense, work may be the opium of the people, like religion was to Marx (ibid.). He contends that, regardless of which stance one takes, it remains to be seen with what activities people will fill their days when the amount of paid work available

decreases (ibid.). I would argue that the shop floor at Spring offers one possible scenario among a myriad of alternatives. Some workers conflated social activities and work tasks, and those who had previously been made redundant gave insights into how they had spent their time when they were unemployed. In this regard, as well as in their wish to change the public's perception of disability, they were similar to the participants I am going to discuss in the next chapter. I contend that workers may also, unawares, be showing us 'what really matters' when work is hard to come by for a greater number of us. In so doing, they may be helping us recast our lives not only by facilitating a more appreciative view of people of different abilities, but also by paving the way for us to reflect on what *we* might consider worth doing when paid work is no longer the default social occupation. How will we fulfil our 'need to be needed' in a world with less work?

Chapter 5. Refocussing the Self: Life After and Beyond Sight Loss

5.1 Introduction

In this chapter I draw on data I collected outside of the factory, mostly from participants from a more privileged socio-economic background and, in order to be true to my interlocutors' opinion that 'every visually impaired person is different' (see chapter 2), I take a biographical approach. I present the stories of two men: Andy, a successful financial professional who crafted a new diary, and a new self, following insidious sight loss and medical retirement, and William, a young man who discovered his vocation as a storyteller after sudden loss of sight. Instead of being obliterated from their life narratives, sight loss is woven into them to reframe not only their professional, but also their broader personal trajectories. Furthermore, both personal stories show how responding to disability can bring benefits not only to the individuals affected by it, but also to those who surround them.

In spite of its biographical character, this chapter has multiple connections to other issues presented in the thesis. The emotional energy consumed by the process of becoming part of the visually impaired community described in chapter 2 is always in the background. Moreover, in line with the chapters on the factory (3 and 4), this chapter gives examples of the importance of the professional side of one's life in creating a new narrative of the self after sight loss, but also of the significance of other facets of 'work' besides paid employment.

5.2 Therapeutic Emplotment between Coherence and Drama, between Losses and Gains

If I obtain this favour (as I hope) it will seem to me henceforth that I have acquired a mirror that I shall always call a divine mirror, because in it I shall see you and me together… And seeing myself vividly portrayed by your art will provide me with a continual stimulus to purge my soul of its many defects, and seeing therein the illuminating rays of

your genius (virtù) will kindle in my soul a noble longing for glory and honour (in Brilliant 1991:129).

These are the words of a 16th century humanist who, striving for his own moral betterment, commissioned a renowned artist to paint his portrait. His superb craftsmanship would crystallise his own life into a single image, which would provide 'coherence and meaning' to an otherwise fragmented existence: the nobility exuding from the portrait would act as a moral compass whereby he would orient himself in life (ibid.). Acting at once as a visual and as a moral beacon, this portrait stands for the narratives that visually impaired people construct with the aim of establishing a new order in their lives. It is an improbable metaphor, as it appeals to the sense of sight, but it is also one that aptly conveys the 'work,' sometimes the exertion, at times the artistry, that they put into re-crafting their lives after losing their sight. This chapter is about the therapeutic emplotment carried out by my individually recruited participants in the face of sight loss. Some of them acquired sight loss, whereas others had been visually impaired from birth or from a young age. As one of my informants pointed out, 'even congenitally blind individuals develop and grow their sense of self with respect to their visual impairment, as their own horizons grow with age, experience and the positive influences of others in their lives.' I show that the concept of therapeutic emplotment applies to my congenitally and adventitiously visually impaired participants, though in each case it may manifest itself differently.

In order to be truthful to this difference, my approach is biographical, and the portraits that punctuate the thesis elsewhere will be at the heart of this chapter. However, I will also present the recurring traits that these stories evince: although it is true that 'everyone is different,' a biographical perspective, like a narrative one, may be more than mere illustration (cfr Barrett 2014). It may help 'move beyond an empty account of difference through the systematic description of *how* and *why* differences are realised' (Schiff 2014:10-11, original emphasis). Among my participants, I found the following recurring traits: the shock caused by sight loss to the sense of self, professional and *tout court*; the long and distressing process of reconsidering one's life; the turning point leading to a new professional and moral career. My participants made me aware of this progression in recounting their life stories, which they shared with me from the privileged position of somebody who had

already found a new meaning in their lives. Yet speaking of a strict progression from shock to distress, from turning point to moral betterment[38] is problematic. I argue that, in the face of such complexity, not even emplotment can provide perfect coherence. I concur with Mattingly that, if narrative is akin to human experience, it is so in virtue of its dramatic nature, not of its coherence (1998a:154). The new narratives of one's life never reach a vanishing point, rather they spiral forward, as the self is always in the making.

In chapter 4 I argued that narrative can take different shapes, and described two different types of narrative that were applicable to workers at Spring. In this chapter, I draw on Frank's distinction between restitution, chaos, and quest narrative (1995), which I found germane to the present discussion. The first one aims to return patients to their previous life, which is reconstituted after the rupture caused by illness (ibid:75-96). The second one is a non-narrative that arises when sufferers have not yet had the opportunity to articulate their pain in a structured and purposeful way (ibid:97-114). The third one entails the overcoming of the negativity brought about by a medical crisis through personal growth (ibid:115-136). It is also a narrative that resonates heavily with the general culture in their locale. There is always a dialogue between community narratives and personal narratives, and both may draw from overarching cultural paradigms, such as biblical stories (Humphreys 2000:504).

The story of redemption can be found at the level of the mundane when people speak of 'healing', but it also characterises, albeit in different ways, many major religious traditions, including the Judeo-Christian one (McAdams 2006:18-19). In America, which is culturally and spiritually strongly influenced by this tradition, and in particular by Puritanism (ibid:27), redemption is in fact a common overarching narrative that is available to people creating their own life narratives (McAdams 2006). In spite of the differences that there may be between the American context and Britain, in Donchester stories of personal growth are also important. Notable for the purpose of this research are stories of disabled people overcoming their

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[38] In Taylor's words: 'accept, adapt, achieve' (1993:14), or again in Murphy's bleaker analysis: 'lowered self-esteem; the invasion and occupation of thought by physical deficits; a strong undercurrent of anger; and the acquisition of a new, total, and undesirable identity' (1990:108).

difficulties (the overcoming narrative described by Bloom, chapter 4), which are very present in the media. It is therefore unsurprising that, among Frank's three narrative types, it is the quest narrative that applies the most to the research participants I present in this chapter. For all of them, sight loss was a disruption they would not have chosen, but they have come to terms with it because it triggered life changes that they came to appreciate. 'Losses continue to be mourned, but the emphasis is on gains' (Frank 1995:128).

Considering how their sight loss compelled them to delve deep inside themselves and develop previously untapped qualities, their stories are comparable to that of painter Sargy Mann quoted at the beginning of the thesis. Blindness led him to rely more on his personal world rather than unconsciously searching the visual environment for the subject matter of the master painters he emulated (2016:29). For instance, after sight loss he started drawing considerably from the scientific side of his personality, in particular from the knowledge in mathematics he had obtained when training as an engineer (ibid:28). He therefore argued that the paintings completed in this new situation were, in some way, truer to his own self than his earlier, visually inspired work (ibid.). Furthermore, Mann contended that artists are not stopped by sensory impairment in their pursuit of 'higher order variables' (ibid:30). These are unique combinations of light, sounds or words created by painters, composers or writers respectively, which convey unprecedented emotions to those experiencing their work (ibid:30-31). In the next section I present Andy's story, including the benefits that, in spite of the ordeal of losing his sight, dealing with this sensory impairment brought to him.

5.3 'Out of the Pit': Andy's Diary beyond Financial Services

The concert halls and art galleries of which Andy is a habitué are spaces of middle-class formation, but his attachment to beauty, a beauty he appreciates particularly in the dramatic arts, music and painting, transpires as a visceral passion rather than an exercise of class-belonging. I am an avid consumer of culture myself, and Andy could easily have enticed me to forget about ethnography and talk about Titian and Beethoven instead. Yet, he keeps his contributions to the point: 'I am your research

tool,' he has told me many times. As someone whose congenital sight loss turned from partial to sever at the peak of his career, he had to face obstacles that helped him become a resilient, albeit good-natured, fighter. He demonstrates his determination by embarking on a master's degree in his middle age, and he is keen on improving other people's work, as well as his own. 'Work,' in his life, has come to mean anything from finance to counselling, from having a good salary to volunteering. By putting himself at my disposal to answer questions and by proactively writing emails to clarify previously discussed points, Andy is also doing the work of helping sculpt my thesis and, indirectly, smoothening a world with still too many rough points for people with disabilities.

'I think there are two things that have made me who I am now: I changed my job, and my sight loss.' Andy is a soft-spoken, gentle man in his mid-50's, and even when resentment creeps up in his speech, he expresses himself calmly and level-headedly. He was diagnosed with a sight condition in his teens, but his family did not disclose this to him until he turned 18. As he was assured by medical professionals that he would not go blind, he stopped going to the eye hospital for a decade. When, in the early 1990s, he went back for a check-up, he was told his sight had deteriorated so much that he qualified to be registered blind, which he did. However, this had 'absolutely no impact' on his busy professional career in financial services, or even on leisure activities. The incident that really made him realize the severity of his sight loss was the following.

> As my career was going up, my sight was going down. And then one day I was at work, and I'd been making some notes. I put my pen down, and I couldn't see it, and I just sat at the desk looking for my pen. I stared at the desk for about 10–15 minutes, and I just didn't see it. Until a member of my staff came past and said: 'What are you doing?' I said: 'I'm trying to see my pen.' 'There it is, Andy.' That was the point I knew I couldn't do it anymore.

Having been a busy professional for years, his life was 'just shattered' by this realization, and after walking out of his office for the last time, his past life was gone. 'Suddenly there was nothing to do all day.' He could not take on any other roles for two years while his eligibility for medical retirement was being considered, but after

six months he started 'the process of coming out of the pit.' What 'put rhythm' into his life was the opening of a gym close to his home. After he lost his job, he had 'just been staring at the wall, waiting for the next thing to happen' Then, he tells me, 'I started off going to the gym in the morning, realising I needed structure. That's where my present diary came from. My entire working life, I had had a diary like that.' That gave Andy a routine, which was soon enriched by activities 'for the mind' rather than 'for the body': he took various short courses and, following confirmation of his medical retirement, he gained a qualification in a speech-based profession: psychotherapy. He also took the opportunity to do some paid freelance work assessing the accessibility of different services to disabled people.

Many years on, Andy's diary is still a driving force in his life. In order to adhere to it as he goes about his day, he has a talking alarm telling him the time. He tells me what he has done over the course of this week, starting from today and going backwards. Yesterday he did some writing, which was actually not in his diary, but which he fit in. On Monday he was busy with work. On Sunday, he took care of some home administrative tasks and did some shopping. On Saturday, he left home at ten am to go to an event for visually impaired people at an art gallery, and came back at three pm. After that, he was just sitting around watching TV. On Friday, he met one client and two supervisees, on Thursday — he doesn't remember what he did. Last Wednesday he had a meeting. All these activities help him keep isolation and loneliness, which often affect visually impaired people, at bay. In this regard, his social life seems quite rich. Written in the different cells of a spreadsheet, which he keeps in his computer, are tactile tours in galleries, audio-described performances and touch tours in theatres, as well as other appointments and meetings. Each activity is listed in a specific time band. 'That gives me a bit of a schedule.' He likes to be organised, all the more so because he has signed up for a Master's degree, which will complement his knowledge of his professional field.

Having a busy agenda can be challenging if the pace of life is slowed down by visual impairment. He complains about the slowness affecting his life with a touch of irony, which is not typical of him: 'The pace of my life has slowed completely, with one exception: eating.' He adds: 'When I could see, I would walk to the station, and it would take me eight to ten minutes, now it takes a good twenty minutes.' Also,

although his sight loss does not slow down the practice of his job as a psychotherapist at all, it does slow him down in the completion of paperwork. 'The log sheet each week takes me twenty minutes to do, whereas my colleagues do it in under a minute.' Also, it takes him fifteen minutes per session to complete his client notes, whereas his colleagues do it in three to five minutes.

Andy looks beyond the problems caused by his disability to consider how his present self has been shaped by it: 'Had it not been for my failing sight, I would not be who I am now, I would not be as good as I am now at the things that I do.' In particular, Andy attributes his professional success partly to the 'fog' that clouds his eyes. According to him, it prevents him from judging clients on the basis of their looks and allows him to engage solely with their words and voice.

Andy has also reconstructed his life around leisure activities, which occupy an important part of his diary. Having been introduced to the theatre as a child, he became a lover of this art form in his youth. His reducing sight and heavy workload then prevented him from going to shows for twenty years, and when he had the opportunity to attend his first audio-described performance as a blind man, he approached it with scepticism. However, he was 'just swept away by it': 'At the end of the performance I just sat in my chair and cried, because somebody had given me back something that I thought I had lost forever.' This reignited his love for the theatre, and was another positive transformation brought about by sight loss: 'When I was working, my life was defined by my job. Losing my sight has opened the door to having a social life.' He has now attended many shows at the same theatre after his first audio-described performance and, every time he and his wife go back, they are greeted 'like friends.' He praises the events organized by the accessibility office at this theatre as something that allows visually impaired people 'to still have a life, to be part of society.' Incidentally, I met him through an audio-description company, which during the early stages of my research kindly agreed to spread the word about my project in order to help me recruit participants.

Andy also praises the work of the rehabilitation officer who gave him the confidence of going 'out with a fearful long white stick and say 'Sod you world, I am actually coming out and being part of you.' This is important to Andy, who bitterly complains

about what he calls the 'me-first' attitude of today's society. Ironically, this becomes apparent to him when he walks around with the same white cane that gives him freedom. He calls it 'my cloak of invisibility': people push past him and treat him as 'somebody else's problem.' They actually ignore him less when he walks with his white stick accompanied by someone than when he walks with his white stick on his own, which is when he would need more help. Andy suffers because of the blasé attitude and the 'inter-human struggle for gain' that characterise life in a metropolis (Simmel in Wolff 1990:420). He deplores the recent social changes, such as budgetary cuts to local services, for instance for community centres, and the growth of online rather than in-person interaction. This, in his opinion, is leading to passivity and isolation: 'Being a social entity means physically being around other people,' which he contrasts, for instance, to the current tendency of doing things online.

Andy is well positioned to comment on social changes, as he has lived all his life in the same working-class (then white, now predominantly Asian) area of Donchester. To illustrate his point, he takes me on a walk around the places where he lived from his birth in the 1960s until the mid 1980s. He leads me to a residential street lined with Victorian terrace houses either side. I describe what I see, until he stops in front of a particular house. 'Look at the upper floor: there should be a window to the right. That's where I was born.' He has not been here for twenty years, and he is saddened not to find 'the beehive of activity' that there used to be. Andy has a penchant for reminiscing about the good times gone by, and for lamenting present social trends. This tendency becomes more apparent as we visit his old neighbourhood: he finds there is 'more sounds of cars, more traffic of cars and less traffic of people.' Listening to Andy, it is difficult to disentangle his overall wistfulness from his particular disappointment to how the world is becoming less accessible to visually impaired people. As a matter of fact, his sight did not pose him any problems when he was still living here. Yet, he does give some concrete examples of what he means by saying that this neighbourhood used to be more accessible: 'shops had doors, they were easy to find, there were people you could ask and talk to.' We continue our walk to a green area, where cows used to graze and provide milk for the local dairy. 'Here in the past you would have heard sounds from the diary, kids…' Nowadays, the area is still and, as I walk along the street telling Andy what shops I see, I describe them mostly by what is written on the board above the door. The

metal blinds are pulled down, because most people shop at shopping centres, one of which has opened only a few kilometres away. I try to play devil's advocate: 'You can find everything you need at a shopping centre, they are convenient, safe and there are shopping assistants.' 'Accessing a shopping centre can be difficult [if I go without a friend],' retorts Andy. He argues that the space is not welcoming, and it is laid out in a confusing way. And then, there is the 'tsunami of people,' which he defines as a dismissive, rather than deliberate, act of aggression. They 'walk into me. I'll get bounced around, I won't actually be seen, and trying to find locations I need to find is a real pain.'

Even when Andy does not get around on foot, his journey can be arduous. He describes to me a journey he made on a bus service run by the local transport authority for disabled and other disadvantaged people. His destination was a twenty minutes' drive away from his point of departure, and he was the first person to be picked up. The bus then collected seven other people, who were all dropped off before him. Andy reached his destination one and a half hours after he had left home, and thirty minutes before the end of the meeting he had travelled to attend. His return journey was not better.

I go into a small chain supermarket with Andy to help him buy some cakes, and the inaccessibility he was describing becomes apparent. I take him to the cake section and tell him all the names of the cakes and biscuits that are available. After he has chosen, we go to the tills, where we are invited to use the self-checkout machine. Andy says he cannot use it (the ever more present touch screens are always a problem for visually impaired people), so we wait at the manned till, where he pays cash. As we walk outside, he tells me it would have been impossible to shop without me, as there were no assistants to call, and narrow lanes were made narrower by crates of goods. Even his local gym, the one that allowed him to restructure his life around a routine, has become less accessible. He exercised there for around seven years, but then he had to stop because the hours when there was an instructor available to help were reduced and, even when the instructor was there, they were booked for private training. Moreover, touchscreens were introduced, which made the machines more difficult for him to operate.

From what has been said above, being spatially active is not easy for Andy, who points out: 'Great we can learn routes to go to different locations, but you are reliant on [them] not digging up the road, not parking on pavement. If they do do that: it can be absolutely lethal.' But this does not mean that he needs to be physically mobile in order to travel, at least in his imagination. When I visited his home, he showed me his 'solitude space,' the sparingly furnished room where he retires to write or think. 'I can go into that room, sit on the sofa, feet up, close my eyes, and I could be sitting on a beach in Venice in my head within moments. I can be at a brilliant concert, sitting in a restaurant. My imagination could be running all over the world.'

Still, Andy's independence is increasingly compromised by his failing sight, as well as by the world around him. The independence went when his central vision collapsed, he explains, not when he lost his job. He emphasizes the difference between those who have never seen and those who were able to see and lost their sight. 'As sight fades,' he says, 'there's always one more thing you cannot do.' He even goes so far as to say that he has sometimes wished to wake up in the morning and be completely blind, deprived of the peripheral vision that he still has. 'I would not have to keep relearning to live, fighting to do things.' When I ask him what independence means to him in practice, his answer is: 'That I don't have to rely on somebody else to do the most basic and simplest things.' He adds with frustration: 'I've already got a note in my diary when I am gonna go with someone and get my Christmas card and gift for my wife. It's the beginning of bloody November. But I have to book it in, because she [his friend] gets busy.'

From the above passage it appears that, if on the one hand having a diary has helped Andy restructure his life after he lost his job, on the other it constrains him. Another consequence of sight loss is that:

> *The ability of being spontaneous really fades. The thing for me that burns most, is: I could buy a card for my wife, I could buy her a present, I could go into a shop and look at the cards. These are the things I lost most. I would be in the shop for an hour, trying to find exactly the right card. I can't do that now. I have to go with somebody else, and they'll be the ones picking the cards.*

Reflecting back on his life trajectory, Andy is relieved that his medical retirement happened before the introduction of the Equality Act of 2010 (which replaced the less stringent Disability Discrimination Act of 1995). He argues that, had his employer been required to put in place 'reasonable adjustments,' his own role within the organisation would have been compromised: 'I could get medical retirement, I could move to [other town] at my own cost and work in a call centre, or I could take a reduction in my job by four grades, and work for somebody who was crap at their job, and basically do most of their job for them.' His income would have halved, and he would be earning less than he now receives from his pension. He explains: 'I was in a well-paid job. If I had to change job [because of my medical condition]: I would not have been able to save that money. I would not be sitting talking to you, study, take on the roles to help people change their life [through my current job]; I would not be able to financially afford it.' Given the situation at the time when his sight deteriorated, he chose medical retirement, which enabled him to 'redo' his life, and made him 'step back' and 'revaluate' who he was. He sat down and, over the course of two weeks, wrote a list of his skills and passions, which he then edited with the help of two people whom he really trusted. Fifteen years on, he is involved in different 'jobs.' He uses this word regardless of whether the positions are paid or unpaid, but he carefully tries to create a balance between the amount of work he does pro bono without the possibility of claiming expenses, which he finds more fulfilling; the work he does for free but for which his expenses are reimbursed; and the work he does for pay, which complements his medical retirement pension and allows him to support both his pro-bono professional activities and his leisure. Out of fifteen different roles he has taken on over the last year, only three have been paid. Also, most of the work he has now is the result of the referrals he has received over the years, and he is pessimistic about people with disabilities being given a fair chance in employment. Looking back to his time in the financial services sector, he says: 'Before I had to say I had a sight problem I applied for fourteen jobs; I got twelve of them. The moment I had to declare it, I applied for eight jobs, got nothing, no interviews.'

His current life in general is quite busy, and he gets a bit temperamental when sight loss charities notify him about an event only one week in advance: 'It's too short notice, I've got a life!' Thanks to the Excel spreadsheet where he writes all his

engagements, which he has been keeping for years, he can notice how some activities have been taking up more or less space as time progressed. Overall, Andy now appears adjusted to his life, though somewhat embittered by a society that he perceives as more and more egoistic, and politely frustrated about his daily challenges. In fact, he said he joined my research project because, in his opinion, if you do not speak up about what you are unhappy about, then you cannot complain about how things go. Andy is also concerned about his eyes. Looking flawlessly bright blue, with no hint of disease, they make his visual impairment as invisible as he himself is when he struggles with his white cane to navigate the disorienting space of a shopping mall.

5.4 Therapeutic Emplotment and the Multiple Facets of 'Work'

Andy did not use the word 'bereavement' to describe the distress he felt after losing his job, and the loss of self-esteem, routine and lifestyle that came with it, but this metaphor[39] appears too frequently in the tales of my interlocutors, as well as in the literature, to be ignored.[40] Father Thomas J. Carroll, a pioneer of the rehabilitation of adventitiously blind adults, compares blindness to death, in that it presents a blow to the person's self image (1961:11), and he says that only those who have done the mourning of sight can be reborn (ibid:12-13). Similarly, Mary Taylor, who herself lost her sight (1993:14), argues that sight loss is like the loss of a dear person, and that bereavement can help to come to terms with it, as long as one does not dwell in sadness for too long (ibid.). Numerous autobiographies of visually impaired people also equate sight loss with death (e.g. de Montalembert 1986[1982]:25, see also Malti-Douglas 1988:29). Sight loss brings about a loss of skills and habits, which in turn results in a feeling of having lost a part of one's life, which again may lead to a more existential sense of doom. Unlike death, which comes unquestionably,

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[39] See also blindness itself being used as a metaphor for death, as closed eyes are associated with darkness, and darkness with death (Barasch 2001:43, see also Kleege 1999:30).
[40] See also Whitehouse on the metaphor of 'coming out' to describe revealing one's sight impairment to others (1990:66). In this particular case, Caroline James had adapted to her sight impairment so well and was so skilled at taking care of her appearance that she found it difficult to 'come out.'

irrevocably, sight loss, no matter how severe, can be initially ignored. In fact, there can be discrepancies between the physiological and the social unfolding of the sickness (see Brodwin 1992:91). One of my participants told me: 'In one way I didn't think of myself as not being able to see, but on the other hand I knew I couldn't, because I would never appear as if I could not.' These words are the post-factum rationalization of the chaos narrative (Frank 1995:115-136) this person was living shortly after sight loss. Facing reality is not always easy: it is easier to conjure up intricate convolutions, and get lost in them. 'I had lived my entire life pretending that I was not going to turn blind, I had convinced myself,' Andy told me. Sometimes, my participants' confabulations with themselves are cemented by the opinion of influential parties, such as doctors trying to keep the flame of hope alive by promising a cure that, they purport, is just around the corner. It is surprising to see how such conjectures, sustained over months, sometimes over years, crumble at the weakest wind: a pen on the desk that needs to be fumbled for, a text message that cannot be read not because it is unreadable or illegible, but because it is now forever invisible.

What remains after the crisis is 'a spiritual void and an inability to cope' (De Montalembert 1986[1982]:12), a blank canvas that the person has to confront, a mirror that does not reflect her face when she is looking straight into it. And yet, shrouded in coerced passivity, the self is already at work to reshape itself into something meaningful: 'dead to [its] past life and not yet reborn to this new one' (ibid:25), it goes through the 'extraordinary labour through which [it is] giving birth to [itself]' (ibid.). If death is 'the ends of life' in the sense of the terminal moment of existence, it is also 'the ends of life' in the sense of existence's most profound purpose (cfr Kavedžija 2020). It takes a lot of work to reconstitute the meaning of a life that seemed to have been terminated by a traumatic event. Nevertheless, shards of glass eventually coalesce into a kaleidoscope, lives lean towards ordered stories as ineluctably as systems proceed towards entropy, because 'to name the origin of the pain is to seize power to alleviate it' (Good 1992:45). The metaphor of bereavement may not be entirely fitting to describe sight loss in all cases. As one of my participants pointed out: 'I would not say you have to let your sighted self die, 'cause your sighted self is not who you are: you have to let your ego die, 'cause otherwise you will never accept what is happening to you.' However, bereavement

shares with sight loss a progression in stages, from anger, to denial, to acceptance. At the beginning, life is 'chaotic.' It is shaken by a 'biographical disruption' (Bury 1982) that upsets the relationship between the individual's 'internal and external reality' (ibid:171), i.e. between a life path that was predictable to one that becomes unfathomable because of the diagnosis. In the end, life finds a new, though precarious, equilibrium.

The 'work' of searching for this equilibrium or, to use Andy's expression, of 'coming out of the pit,' may take many forms. One of my participants pushed herself to disclose her disability to others following the breakup of her marriage. Another one decided to undergo enucleation in order to put an end to his physical suffering. Again another one took the same decision, but for aesthetic purposes, which slightly increased her confidence. Coming to terms with using the white cane, which can be seen as a 'badge of disability' (Taylor 1993:26), was described by many of my informants as a turning point in their lives. As the self constructs itself through its use, it can be defined as a biographical object (Hoskins 1998:21). Yussef, whose portrait I present in chapter 6, had been declining to be taught how to use it because of shame, but after moving out of his parents' home as a student and realising how dependent he was on other people, he proactively asked to learn. A few years on, his outlook on the matter has completely changed: 'I feel very pretty proud of it now, carrying it around.' For some people, accepting the white cane stands for accepting their belonging to a particular group of disabled people. As a biographical object, it tangibly 'anchors' their emplotting for better or for worse. When she is walking around town on her own, Dietlinde (chapter 1) listens out for the tapping of a cane in the hope of fortuitously coming across an acquaintance. In so doing, she embraces the little spontaneity that navigating space as a visually impaired person allows, and gives credence to her genuine belonging to the VI community.

The contributions I elicited from my interviewees were often so pithy and expressive that they revealed themselves as the product of a long process of introspection and emplotment. Stones masterly polished by the joint effort of time and wind, they shone bright, and gave away the work of assessing, analysing, filtering, suppressing, enhancing, substituting and remaking of their experiences that had taken place within my participants (see portrait of William, below). Sometimes, my participants

shared with me stories that sounded well-rehearsed, but not less true because of it. Like actors repeating their lines *ad nauseam* for a Robert Bresson film, their character was divested (bereaved?) of its accoutrements and revealed itself in all its truth. As suggested by my description of the use of the cane as a biographical object, the emplotment they performed went beyond the verbal into the 'stuff' of their lives. That is why, from a methodological perspective, ethnographic fieldwork was essential in deepening and nuancing the data evinced through interviews (cfr Atkinson & Silverman 1997). For some of my participants, carrying out emplotment in their lives started by sitting down and making a list of their strengths, skills, interests and passions. For others, it began by giving in to a nagging friend and starting to go on tandem rides. From this, it becomes apparent that, in contrast to what I have written above, people suffering from sight loss were not facing a blank canvas. Perturbed but not destroyed, the image of themselves preserved a halo of who they had been before. As a matter of fact, successfully resuming past hobbies was repeatedly reported to make them joyfully come to life. When Andy told me about his reignited love for the theatre, he contrasted it to his distress at having lost the ability to read with his eyes, in his mind, independently: 'It's awful when you've got an audio book, [speaks with an affectatious voice] and you've got an actor overdoing the words, overdoing the language, [stops speaking with an affectatious voice] rather than just reading it.' All that was left to remind Andy of the pleasure of reading a proper book was an old copy of Shelley's *Frankenstein*. A long time ago, he managed to get an old edition of this book. He went around until he found a man willing to rebind it in exchange for a bottle of wine. After the man completed the job, Andy gave him twenty pounds and two bottles of wine. Still a treasured 'biographical object' (Hoskins 1998), that copy of Frankenstein now sits on Andy's lap when he — lying on a sofa, his feet up — reads poetry or a short story in audio format. It is interesting to notice that, in my contention that emplotment often goes beyond the verbal, I concluded by describing a biographical object made of printed pages.

It is perhaps less surprising that education was mentioned by many of my professionally successful participants as a determining factor in their lives. Those of my participants who could receive a good formal education also had a wider range of professional chances open to them. I will illustrate this, as well as other thematic threads in the thesis, by presenting Robert, a blind accountant. His story is, in a way,

exceptional: a limited proportion of visually impaired people have a job, never mind a successful position like the one Robert used to have. In another way, his story resonates with those of other visually impaired people featured in the text. For instance, his professional struggles in an intellectually demanding job is a vocational story that can be compared and contrasted to those of the workers at Spring, just like his response to medical retirement can be compared to the workers' feelings about 'sitting at home doing nothing,' i.e. being unemployed and/or on benefits (chapter 3, 4). It has been argued that lack of work may symbolise one's 'failures in life' (Estroff 1985:164). Being stripped of his professional title threw Robert into a crisis that he only retrospectively labelled with a term he heard about by chance in the media: 'loss of identity.' The effort he put into tackling this crisis was less the fruit of chance than of his rational appraisal of his strengths and weaknesses. A conscious resolution had been at the heart of his decision to enrol at university to become an accountant in the first place. He made this resolution following a telephone conversation he had with 'one of the brightest people [he had] ever met.' Robert remembers talking to this person, an alumnus of his school, from the phone booth at his high-school. When Robert confided his wish to pursue an academic education to him, the latter encouraged him to 'aim for the stars.' Thanks to his good A-level results, Robert got a place at the university he had marked as his first choice, and he went on to fully qualify as an accountant. This would have entitled him to simply go through the recruitment process, but the prospective employer decided to interview him. Robert, who was aware that this was an additional trial caused by his disability, managed to turn the situation to his favour and to crack a joke that guaranteed him the job.

Robert worked for twelve years in the corporate environment, where neither the layout of the office nor the attitude of employers was welcoming to people with sight loss. Given the problems presented by the open-plan structure of the hot-desking working space, such as trip hazards and constant flux of next-desk colleagues, he demanded and obtained a personal office. Other battles were harder to win, however, for example that aimed at having constant, guaranteed access to computer systems accessible to his screen reader. Robert talked about his struggle to be put in a position to perform his job properly: 'you can fill my day with things I can't do, and I'll be useless; you can fill my day with things I can do, and I'll be very valuable.' Thinking more about the challenges he faced at the office than about his journey to

work, he concurred with blind BBC presenter Peter White that 'most blind people have already done a good day's work before ever they make it to the office or the factory' (1999:255). This extra 'work,' which I have discussed in relation to Spring workers' long journeys to the factory and to their 'second shift' at home, seems to be the cloud to the silver lining of being employed. But a totally different type of 'work' awaited Robert when his ophthalmological condition deteriorated so much that he decided to apply for medical retirement: the narrative 'work' of redefining himself, professionally and personally. After weighing the consequences of this decision against those of other options open to him, he eventually decided to retire in his 30s. He called medical retirement an 'all or nothing' process, and one that 'defines you.' Because it was impossible for him, due to the nature of medical retirement, to be active either in his profession or in others, he suddenly found himself with nothing to do for fifteen hours a day.[41] He told me: 'Employment saved me from destructive boredom for a large part of my adult life, twelve years. After retiring, I no longer had that structure.' Like other visually impaired people featured in the thesis, he eventually found other activities to pursue in his abundant free time.

Writing about a specific social context, unemployment in Northern Ireland, Howe stated: 'Employment is the activity which integrates, justifies, and gives meaning to many other relationships, interests, and pursuits. Once work is lost, the whole edifice seems to fragment' (Howe 1990:215). I would like to use Robert's story to dwell on the repercussions that being stripped of his professional role had on him, and to reflect on the question 'How will people's social identity be determined, if they no longer have to tell themselves and others that 'what they do in life' is one of the standard occupations?' (Beck 2000[1999]):63). The sense of emptiness conveyed by this rhetorical question is echoed by Robert: 'The single biggest loss for me, which was unexpected, was no longer having that identity, no longer knowing who I was.' Back then, he said to himself: 'I am not in employment, but I am not unemployed, because I am not seeking work.' It was only later, when listening to a radio programme on 'loss of identity' in a different context, that Robert was given a label that helped him emplot his own situation. Prior to that, his sense of loss used to turn

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[41] Contrast this to Kavedžija 2019a:226 – 227 on Japanese artists quitting their job in order to have more time to concentrate on their passion.

to anguish whenever he was asked one of the most frequent questions in small talk: 'What do you do?'[42] The process through which he developed an answer is a further manifestation of the narrative 'work' that visually impaired people have to perform in situations in which most people can react effortlessly. At first, Robert would shun social encounters where people may ask him that question, or rely on a friend to deflect the question for him, or again lie by saying he was an accountant, and then quietly add that he was retired. He found that, however, a suboptimal solution, because he sensed that people did not hold him in the same esteem as they did when he was still a practicing accountant. Now, although he has not found an answer as straightforward as his old job title, Robert has come up with a series of phrases that he may choose from, according to his mood and to whether 'he is caught off guard.' He may reply that he is retired, but does voluntary work, or even talk about his citizen activism, an activity he does on a voluntary, and low-key, basis. People usually react interestedly, and this stimulates the conversation.

In sum, the question 'What do you do?' which was initially emplotted as perturbing, has almost become a social lubricant. Moreover, as I was hinting at the beginning of the chapter, such adaptation process takes an ever-evolving form. To anticipate what will be said in the portrait of William, the solution that Robert has devised for himself even allows him to break away from the mould of this professional persona. Without dismissing the hardships he encountered when leaving his job, and his sadness and bewilderment at being left without a clear identity, his current position is more pregnant with possibilities and open to self-crafting. If 'wellbeing is […] less a reflection on whether or not one has realized one's hopes than a matter of learning how to live within limits' (Jackson 2011:61), it is important to consider that, looked under a certain light, limits may be not constraints, but just narrower pathways towards a different existence. What counts is having the initiative to open up these pathways, and the energy to pursue them. Narrative can be a way of opening up and pursuing these pathways, as 'stories are a way of redrawing maps and finding new destinations' (Frank 1995:53).

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[42] See Susskind 2020, who observes that there is a presumption that what we do professionally says something about ourselves.

Robert managed to successfully redraw his personal and professional narrative in spite of, or thanks to, multiple factors. In regard to the obstacles, it should not be forgotten that personal narratives are embedded in narratives happening at a broader social level. Indeed, Frank has argued that institutions can lead people to adopt certain narrative frames (ibid:77). In particular, the restitution narrative is favoured by the medical establishment, which, in this type of narrative, exercises agency at the expense of the passivity of the patient (ibid:91-92). In William's story we will see him rejecting this pattern: he did not want to 'be taught how to be ill by professionals' (ibid:159), instead, he wanted to embrace a quest narrative.

In Robert's case, it was his family members who failed to cooperate in his narrative work. They failed to follow him in the development of a meaningful narrative about his life with sight loss, which made his interactions with them straining. For instance, some of his family members frequently referred to the visual cues in the surrounding environment, thus excluding him from the conversation, while others, even years after his medical retirement, kept asking him whether he had found a job. The fact that emplotment is embedded in a specific culture or family does not necessarily mean that culture and family are therapeutic; in fact, they can be an obstacle to reaching a positive equilibrium.

Among the positive factors that helped Robert develop a new narrative of his life was his luck, which he recognised to have played a big role in who he had become. In fact, although I have emphasised the personal determination and effort invested by my participants in the making of their lives after sight loss, circumstances are also mentioned in their comments. Favourable or adverse, they are one of the raw materials that are utilised to build their coherent life stories. 'For everyone who's successful, luck must play a big part, and it was indeed very important in my life,' Robert remarked. He then listed the incidents that, in his opinion, shaped his life for the better, and also the determining encounters he had with significant people, like the inspirational teachers he had in school and the inspirational people he met at university. His three milestones, in his view, were having the opportunity to receive first-class secondary education, obtain a degree, and pursue his career. Each step built onto the previous one, in what he calls a 'cascade effect.' 'If each of those had been different, the people I met had been different, the results would have been different.' Even so, he acknowledges his own strong will. In fact, he thinks that he

was also lucky to have the mindset to take advantage of the opportunities he was offered.

Other participants attribute a more profound, spiritual meaning to the serendipity that affects their lives, in particular their lives as people with sight loss, and the way in which they have managed to incorporate their disability into their lives. Because religion may provide a framework for emplotting one's life, the nexus between spirituality or religion and disability is a productive locus of enquiry (see Selway & Ashman 1998, for a historical perspective see Schuelka 2013), as is the role of religion in influencing disabled people's politics of self-representation (see for instance Zoanni 2019). Among my research participants, spirituality or religion did not emerge as prominent explanatory factors on the basis of which life was emplotted. However, for some of my informants, like Yussef, divinity was very significant:

> *I guess I'd always heard about that whatever God does is good for you, and that he has a plan for you, and I guess I understood it, but maybe I was not really convinced, but there have been loads of things that have happened in my life and some of which I realised after a couple of years that 'Oh, this was really the best route for me,' and I can't believe why I was so sad about it at the time. I just feel that God was present at that time and was, you know, doing everything for my best interest.*

Just as Robert considered luck as one variable in the equation of his life, so did Yussef's worldview allow space for human agency: 'God has given you, say, ten different paths, those are written for you. Which path *you* choose depends on you' (original emphasis). Yussef's belief in God was important also during moments of distress caused by his ophthalmological condition: 'I was in a lot of pain, but I did not forget the presence of the Being that had saved me, that had given me life, and given me all the wonderful things.' Yussef was rare among my participant in that he laid such a strong emphasis on faith when he emplotted his life, and he was unique in bringing up how God could screen him from various manifestations of immorality. When asked about the benefits of his blindness, besides mentioning positive encounters that would not have happened if he had been sighted, he said:

A: I do feel that it's definitely benefitted me in so so so so many ways that helped me prevent looking at bad things as well, that my eyes would force me to see otherwise.

Q: Such as?

A: Well, such as obscenity, such as nudity, such as, you know, bloodsheds, such as violence towards other people that you can see, all of those things. Distressful things as well.

When I spent time with Yussef and he stumbled upon some of his friends (or, rather, *they* saw *him*, and approached him), his assertion that he did not judge people on the basis of their looks but rather on the purity of their heart was substantiated. Most people claim to do this, but only when I was with Yussef did I see this moral sanction enacted. In micro-interactions among sighted people, it is impossible not to discount appearance, and give away one's aesthetical judgement. Yussef, on the other hand, who has almost no recollection of sight and has no canon of visual beauty, gracefully navigates social interaction without being distracted by details that are unpleasant to the eye.

What I found more widespread than religion proper among my participants was the positive meaning they attributed to the consequences that their disability had had on their personality, in particular on their interpersonal qualities. Incidentally, this phenomenon is present among people with other conditions (see Miles 2009:7). As described above, advent of sight loss was accompanied by anger, disbelief and dejection, but when such phase was overcome, there was room for other feelings to come to the fore. In other words, sight impairment was 'welcomed back' (Watermeyer 2009:100) into visually impaired people's lives, who learnt to live with disability, rather than either succumb to it or hope to be cured (cfr Wool 2020:313). Undoubtedly, frustration and anger were never conquered, and at times re-emerged against oneself and others. However, none of my interlocutors said that, in the grand scheme of things, their impairment had made them embittered or resentful. On the contrary, they referred to the 'enrichment of life' (Watermeyer 2009:97) brought by their disability, and laid emphasis on their enhanced tolerance towards others and determination. When asked to recall an instance in which she had demonstrated the

determination she gained through sight loss, Dietlinde (chapter 1) recounted how she had stubbornly struggled to move a sticky cake from its box to a plate. In equally mundane but more social contexts, I often noticed the resolve with which some of my informants stood up for their rights, or for those of their fellow visually impaired people. Crucially, sight loss and its effects were not discounted from their narratives, but embedded into them as an element that, alongside many others, such as their personality, family background and chance, had influenced their lives. As William told me, 'My relationship with my blindness has massively improved. There are ways in which I see it as a gift. It was because of sight loss that I found my path.' I have often described my participants' life after emplotment as a *new* life, but in this comment William suggests that he was without a clear direction in his youth and, had he not become sight impaired, he might not have found his path at all. Robert, who describes himself as not particularly patient or forbearing, does regard himself, as well as a lot of other visually impaired people, as having a higher degree of patience, tolerance and humbleness in comparison to sighted people, and in comparison to himself if he had not been blind.

Experiences reinforcing my informants' therapeutic emplotment were necessary insofar as any equilibrium reached is always in peril. This will be the focus of the remaining part of this chapter, which will lay the foundations for the discussion in the next chapter. The precarious nature of visually impaired people's therapeutic emplotment was due to the fact that they had to constantly negotiate their physical position in the world, among the 'tsunami of people' mentioned by Andy, or in the subtle social situations described by Robert and William. This necessity was not merely psychological: as outlined in chapter 1 and in Andy's portrait, sight loss can change, and the patient has to relearn to carry out many daily activities in a different way. Visually impaired people also had to reinstate their desired persona within themselves: Andy, who grew up in the 60s, admitted finding it hard to shed the label of 'cripple' from himself, as in his youth this was often attached to disabled people. Finally, they had to reassert their position in society, just as Robert had to manage to introduce himself at every new social gathering by circumventing the problem of not having a clearly defined professional identity. Some participants admitted still harbouring anger at having lost their sight, an anger that may be generic, or that may be directed towards oneself, for example for not having had an eye test until the

disease had already progressed, or towards others, for instance towards one's parents, from whom they had inherited the medical condition causing their sight loss. In other participants' utterances frustration was a recurring theme (see Andy's portrait), while others even spoke of humiliation (see William's portrait). In such instances, 'biographical objects' (Hoskins 1998) could be deployed as tools to bolster their confidence and remind them of whom they had become. Andy may sit down at his computer to organise his diary in a word document or, when feeling 'fearful, worried, or about to be challenged,' he may listen to a particular song that improves his mood.

A shift between hope and acceptance often characterised my participants' stance. Both attitudes have a passive connotation but, for some of my interlocutors, hope, in particular hope for a better self, and challenge went hand in hand. As Yussef told me, 'The only way you will grow is if you do things that are challenging.' In fact, some of my participants still set themselves challenges of different types. Here I choose to single out sports challenges, as they seem to illustrate particularly well how the lesson of therapeutic emplotment could be reiterated and reinforced in oneself. Laura, who has tried a wide range of sports, is especially fond of sailing. For her, it is a social activity: 'It gets me out of the routine, out of the house, it gets me a week of fresh air.' More importantly, it is the only sport that gives her the opportunity not only of being in charge of her own movements, but also of being responsible for the preparation of the expedition.

Sailing is the 'making of people,' she told me. '*You* are on the boat, with your own resources, with what you have on the boat. If a mast snaps off, *you* have to fix it. It is about survival.' There are instructors who will not leave her in charge of the vessel, but those who do offer her a chance rarely given to visually impaired people: that of being in total control of their own life and others'. Laura qualified as a day skipper, and is technically licenced to skipper a yacht of up to 50 feet in length, during daylight hours, in coastal waters. She remembers the course, which she took with a sighted helper who conveyed to her the visual information necessary to the task, as 'the single most stressful thing in [her] life.' She passed both her theoretical exam and her practical test, which culminated in a five-hour passage that she had to plan single-handedly. 'I had to manage the boat, manage the crew, avoid other boats… I

was in sole charge of that. It was an amazing achievement; I am proud of it.' A sense of freedom was palpable in Laura's words and, although she did not say it explicitly, I discerned that something more profound was harbouring in her enthusiasm for the successful passage: a reiteration of the overcoming of the difficulties posed by a declining sight, an overcoming that she had demonstrated in many other domains of her life. I quote from our interview: 'Inside the yacht there are few horizontal lines, the shape of the hull is slopey, there are lots of funny shapes. You may bang your head at any time. It's a challenge to orient yourself in this new world.' Thanks to joining a sailing expedition every summer Laura could, in a world that was different because of its spatial configuration, re-enact the adaptation she had made to a world that was different because her sight was ever more limited. In other words, the sense of freedom, responsibility, independence and fulfilment that came with controlling a vessel was akin to the one she, and my other participants, had felt whenever they had managed to live *with*, rather than in spite of, visual impairment. It was such concrete experiences that gave my interlocutors the 'continual stimulus' to anchor the precarious results of their therapeutic emplotment to more stable ground.

In sum, for Laura as well as for my other participants, the process of therapeutic emplotment had to be sustained in order for it to be effective in the long term. It is my contention that, just like the portrait commissioned by the 16th humanist, the life of each of my participants as emplotted following sight loss guided them in their relationship with themselves and, as I will explain in the next chapter, with others. Amidst the turmoil of therapeutic emplotment as a process, the product of this process, i.e. the newly crafted narrative of one's life, could act as a moral compass for my informants. In other words, in the constant struggle of making disability a non-despised part of who they were, their emplotted life constituted a personal capital, the precious crystallisation of the work of acceptance and adaptation and that they had done. As the product of a long and difficult journey of self re-discovery, such emplotted life could be looked up to, and could make the newly found equilibrium less precarious. This personal capital was something they could go back to, and harness as part of a process of continuous re-discovery.

So far, I have unpacked what was important for my participants' emplotment from their own point of view. Appropriating the white cane as a significant biographical

object, rediscovering past hobbies, pursuing an educational and professional pathway and, crucially, new activities that gave meaning to a life without a job title were all significant elements in the narrativization of their lives. Having luck, the attitude to seize it, or faith in a god were also pointed out by some informants. I would contend that what was not explicitly brought up by my participants, however, is also worthy of consideration. At the beginning of chapter 2, I mentioned the socio-economic disparities that characterise British society, and pointed at the complexity of conducting an intersectional analysis of the factors influencing the lives of my informants. Here, I focus on social class and give a summary of how it may be one of lenses through which to look at the narratives described in this thesis.

The preceding chapters presented the narratives of visually impaired people as different as factory workers and ex-financial professionals. I refer to some of my participants as 'working class' or 'middle class' to give the reader a very broad indication of their financial and professional circumstances, but social class was only rarely mentioned by my participants, regardless of whether their socio-economic status was high or low. This may indicate that class is not a category through which they spontaneously choose to analyse their own lives, all the more so since, as a researcher, I did not explore class as a topic and avoided the methodological fallacy of imposing the category of class onto my data (Devine 2004:192). At the same time, it is important to bear in mind that people may still recognise that inequality creates rifts in society that run along class (as well as other, for instance ethnic) divides (ibid.). What the exact nature of these divides is, however, remains to be determined: in her historical overview of the literature of class in Britain, Devine refers to authors who revealed that the emic criterion to talk about differences between people was having more or less money, rather than doing a non-manual versus a manual job (Goldthorpe et al. 1969 in Devine 2004).

My participants were generally silent on how their own socio-economic position had influenced their life histories and vocational trajectories. It is only possible to speculate whether this may be due to the assimilation of a neoliberal ideology of meritocracy. According to this ideology, inequality of outcomes can be ascribed to lack of hard work (Snee & Devine 2018:1143), and *individual* morality, rather than structural forces, is blamed as the cause of failure (ibid:1145, see also Bennett

2013). There were, however, notable exceptions: Laila (chapter 2.1) lamented how being black and with limited financial resources made her circumstances as a visually impaired person even more difficult. Robert (chapter 2.6) acknowledged that it was thanks to his working-class background that he had been given the opportunity to go to a good school and develop a better career than he would have otherwise. Amir (chapter 3.4b) claimed that, if he had received a better education, he would not be working on the factory shopfloor. Apart from these exceptions, my informants seemed reluctant to point out how social class, as well as other structural factors, had affected their own lives specifically. As it has been noticed elsewhere (Devine 2004:97), they were more likely to express generic comments, for instance on the better chances enjoyed by more educated, wealthier people.

Nevertheless, an analysis that goes beyond what was verbally formulated by my participants shows how the narratives described in the thesis may be explained in the light of social class. This is particularly noticeable in the case of the factory workers. The workers' distinction between 'upstairs' and 'downstairs' (chapter 3.4b) resembles the one between 'them' (employers) and 'us' (workers) typical of the working class (Devine 2004:193). Also, chapter 4 described the counter-productive narrative according to which Spring was the only place where the workers could be employed. I argued that 'emplotment requires freedom of action' (chapter 4.4), and that the limited range of tasks that the workers performed on the shopfloor did not allow them to explore their full potential, and therefore to envisage themselves working at a different company.

The sociological literature on Britain is helpful to identify social phenomena and trends that explain the context in which my participants formulated their fears, hopes and aspirations. Griffin et al. show that depression and anxiety were higher in men and women with low control either at work or at home (2002), thus bringing evidence to the detrimental effects of lack of initiative at Spring. Moreover, in their review of the literature on the relationship between psychological morbidity and social position and control, they present different models explaining the interplay of stressors in the professional and in the domestic domains. For instance, the 'spillover model' looks at how strain at work can exacerbate strain at home and viceversa, while the 'double exposure model' recognises the different types of stress posed by different

environments (ibid:785). These models give theoretical substance to the context that shaped my participants' narratives. For example, the 'double shift' that allowed my participants to demonstrate their capabilities as visually impaired people in both the professional and the domestic domains was also something that consumed them, as Jim himself pointed out (3.5). Furthermore, the fear of unemployment that permeates the workers' narratives emerges as the fruit of structural factors that are more or less pronounced depending on social class. The incidence and length of unemployment were higher in people from a more disadvantaged social class in the last decade of the 20th century (Goldthorpe & McKnight 2004:9), a period when most of the workers at Spring would have been in the early stage on their careers, and when they would have forged their ideas about the world of work. The same report shows how the earnings of people from a lower occupational class plateau at an earlier age than those of employees from a higher occupational class (ibid:21). Unless the people employed in menial jobs manage to transition to a more skilled profession, they may be affected financially (ibid.). All this evidence substantiates the lack of opportunities and the low level of income that fuelled the pessimistic narratives of the workers at Spring.

If the above discussion helps explain how the imaginaries of my participants in more precarious, less well-paid jobs were shaped, how can class as a category shed light on the narratives of my middle-class participants? As in the case of Robert, who was projected into a respectable, highly remunerated post by the academic opportunities he received, education seemed particularly important. In fact, in Britain it is normally regarded as 'the key institutional pathway to upward mobility' (Snee & Devine 2018:1134). In my research, having had the opportunity to study seemed to matter more than money when it came to being capable of imagining desirable futures for oneself. For instance, after William (see his portrait in 5.5) lost his sigh, he was penniless, but he could revisit the knowledge of literature he had absorbed in his family as a child in order to develop a career in storytelling. Had his parents been less well-educated, his range of opportunities may have been more limited. It can be noticed that, even within the group of informants who could be broadly classified as working class, having received better training helped with the creation of therapeutic narratives. If Jim felt less 'stuck' at Spring than other workers did, it was perhaps

thanks to the long list of NVQs that he had completed, which had allowed him to find jobs in various companies throughout his career.

This thesis discusses both work in the strict sense of the term and 'work' in the broad sense of the term, i.e. anything to which individuals may apply their time and effort to in order to gain some (financial or non-financial) benefit. Similarly, it may be argued that the measures used to assess the appeal of professional jobs may also be used to measure the attractiveness of non-remunerated occupations. For instance, task discretion is a parameter used to assess the quality of jobs (Green, Felstead & Gallie 2016), and in chapter 4 we saw how Spring workers' lack of agency in regard to task choice constricted their capacity to imagine themselves in other roles. A similar logic may apply to volunteering, or even leisure. The fact that Andy and Dietlinde, who could both be described as 'middle-class,' had therapeutically emplotted their lives in the face of sight loss was also a result of the wide range of activities that they, thanks to their better prospects and financial standing, could take part in. In sum, although social class was not a category frequently evoked by my participants, it can contribute to an explanation of the types of narratives they developed.

One of these narratives was William's, a storyteller. His case was a special instance: by discovering storytelling as his vocation, he made of narrative a career, as well as a trigger for developing a new sense of self. In the case of many other informants, who practiced or had practiced other professions, only the latter function of narrative applied. It was simply, but importantly, the 'illness narrative' described by Kleinman (1988), which helped them revisit their lives perturbed by the advent of visual impairment, and offered a new coherence. In the portrait that follows, William's case appears particularly interesting because, as a storyteller, he fed on the quest narratives of the stories and myths that helped him develop his own quest narrative after sight loss. His story also anticipates the topic of chapter 6: as he now shares his stories and, indirectly, his personal life story, with his audiences, so do visually impaired people create narratives that are models for other people's narratives and that are co-constructed.

5.5 'Artfully Vague': William's Blurred Sight, and His Enlightened and Enlightening Life

'I don't understand the concept of "work-life balance,"' William once told me. What he meant was that, when one does a job because of the intrinsic motivations it provides, there is no need to create a buffer against the stress factors caused by one's professional life that impinge upon one's personal life. Unlike the factory workers in the previous two chapters, who were indifferent to the products they made, William treasures the magic that his tales are made of, so much so that he tries to imbue life *tout court* with their suspense, poetry and wisdom. Describing the conversations we had about his life as visually impaired as 'interviews' would be belittling. We may be sitting in the nondescript, noisy foyer of a public library, but the attention he captured from me was no less acute than the one he obtained when I, as a guest, sat on the floor of an atmospheric venue to attend one of his storytelling events. The following is the portrait I made of William, with whom I also went on long walks in parts of town familiar to him but not to me. Was he the guide, who told me about his experience of those places over time, or was I, who had to warn him of uneven pavements or low-lying branches? Was I the interviewer, or was he, who, with his tales, triggered in my mind questions that dwarfed mine?

'Hopefully I did something to create an image in people's minds.' I meet William at a bar in a poorer but up-and-coming part of the city, where he is performing at his storytelling event. The walls of the venue are packed with artefacts, the ceiling of the venue is packed with artefacts, as if to trap in those who may be scared of the snake that a young man is nonchalantly carrying on his shoulders, as he walks from room to room. It must be hard for a storyteller to conjure images in people's minds when such images are competing with a plethora of artefacts on the sexual, the macabre, and the exotic. Taxidermy, occultist paintings, erotic prints and Dodo bones cram the eyes of whoever, at his peril and enchantment, enters this place. While their sight dances from object to object, William tries to cast fog on their eyes, so that they can be prey to his storytelling charms. Sitting around the table in a quiet corner of the bar/museum, a handful of visitors listen to his voice, deep by nature and malleable by nurture. If all 'human beings are storytellers of the self' (Cohler in McAdams

2014:58), William is a trained storyteller; his long hair flows down his back, his magnetic blue eyes look into the distance, or move to the part of the audience that is most responsive to his tale. Like Andy, the flawlessness of his eyes betrays his visual impairment, all the more so since he walks without the help of a dog or cane. As in the case of Andy, his sight loss suddenly altered his professional life, as well as his life *tout court*. Again like Andy, many years after the advent of his visual impairment he has found a new vocation in a profession that is speech-based.

Interestingly, he describes his art as a way of painting pictures in the listener's mind, while withdrawing enough information to make their imagination take over the creative task:

> *The skill is to use words to make pictures inside your listener. And the lovely thing about this is, sometimes it is good to be artfully vague. 'Cause you don't want to see what you see, you want to see what they see. So it's about keeping it hazy-ish. So the idea is to put pictures in their minds, but also the idea is that the pictures should be emotive. 'Cause describing can very easily get very boring if it's not doing something. If I said 'She brought that blade and sliced, cut into her breast,' I don't need to tell you there was blood. You don't need that, you are there, you've got enough.*

It is interesting to notice that, as an adventitiously visually impaired person, William uses images as a memory aid, as well as a creative device:

> *So when I am devising a story I see the pictures in my mind; sometimes when I am telling the story I see pictures in my mind. When I want to go through a story very quickly, I just watch it like a film, but on fast forward. So I am not laboriously going through every scene, I am just going through the key junctions, the key you need to know is: 'How does this section get to this section?'*

His sight loss also affects the relationship to his audience during the unfolding of a performance:

I can't see their faces, so I can't see if they are yawning, or I can't see if they are looking at me. I can hear the quality of their stillness. I can hear when people are not fidgeting, are not coughing, unwrapping their straps. The first time I had that experience I was terrified. I used to rely on jokes. Then I was given a job to tell a story of loss. It's one of the Viking myths. There are no jokes. The first time I told that I was in a little room, it was very dark, I couldn't even see the shapes of people, just black, which is unusual for me. And I told it in absolute silence for 45 minutes. I was completely traumatised. I got to the end and I said 'Oh, God, I am awful, 'cause I've just been alone, talking to nothing.' Then people started coming up to me saying: 'That was amazing.' I thought: 'Really!?' You've got to learn, you've got to learn to listen. And that's one of the skills of a storyteller: to listen to the audience, as much as the audience is listening to you.

During the break, William tells me how he lost his sight:

It started with my right eye. Within five days I lost all my central vision, although I could see peripherally. I talked to the guy I used to go rock climbing with; I explained to him that I could see the top and bottom of the tree, but nothing in middle. I went to the doctor in February/March, five months later I lost central vision in my left eye. That took four hours. I got on a coach in [name of city], I got back to [name of city], and when I got off I could not see.

After this incident, he found himself immobilised: 'After sight loss, days, weeks after, my body was falling apart. I was seriously ill. Which puts you in a confined space with yourself. It's not pleasant, I wouldn't recommend it, but it can be very creative. And it also absolved me from any pressure to have a normal career.' As a graduate from a prestigious university, William's career chances could have been superb. Still, he confesses, prior to his sight loss 'I had not managed to find a niche in graduate employment. Everything I tried I was deeply unhappy with, although I tried very hard.' He had managed to find a job in a bookshop, but when his sight 'went' (he often uses this expression, as he moves his hand flat down in front of his face), he could not keep it. 'A blind man in a bookshop is just as useful as a vegan in a butcher's. Or a Quaker in a pub.' He was 'absolutely broke.'

His registration as 'severely visually impaired,' i.e. blind, came to him as a surprise. He says he thought the doctor was 'pulling his leg.' Like Andy, he had been misled by the little sight he had left. He received disability living allowance, which made him 'officially severely disabled;' he was overcome by a wide range of emotions: 'grateful, relieved, grief-stricken all at the same time.' Lots of participants have described their experience of sight loss as bereavement. William articulates this:

> *Then you start along the process of grieving for who you thought you were, for who you thought you were going to be, you grieve for all the things you'll never do again, you grieve for all the things you will never do at all, and then you have to start thinking: 'What else, what can I do?' And that's not quick, that takes time. But the funny thing is: this serious illness gave me time. And that is a gift.*[43]

He tried out different skills based on listening rather than reading, until someone suggested going to a storytelling event. He did not even imagine such things existed anymore but, when he went, he 'fell in love.' Because he could not read anymore, he had started, since the advent of his illness, to revisit his favourite childhood books. Many adventitiously visually impaired people have told me of the loss they felt when they realised they were no longer able to read books. In the case of William, this loss must have been particularly acute, as his parents were both literature teachers, and he was read some of the classics when he was a child. The stories he revisited in his mind gave him the material he needed to try and begin a career as a storyteller, but they also provided him with a way to rethink his life. For instance, William remembered a story about a boy, Jed, who was pursued by a black thing that he could not identify or name. Jed chased this thing, and when he eventually put his arms around it, it spoke its name. It was 'Jed,' the boy's own name. William had read this book many times, but it was only after his illness that he understood its true meaning. 'I was 25, and I was confronting the darkness of having to live the rest of my life with the reality that I had been diagnosed with an acutely painful, acutely disabling, progressing degenerative disease. The whole question for me was: "How

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[43] Leisure time is a 'tragic gift' to those without work, according to Marie Jahoda (in Susskind 2020).

do I respond?'" He read a book about his condition, which left him terrified, but also slightly flattered. The author admitted that he should never have written the text, because it described the illness so well that it could shatter the morale of its readers. It also added the unsubstantiated remark that this particular disease struck the most attractive and talented people. Following his wife's advice, William's response was not to follow the path prescribed by the medical profession, and not to name the disease. Twenty years on, he says 'so far — knocking on the table as if to touch wood - so good.' The power he did not seek in medications he found in literature. The protagonist of the novel *Kleinzeit* discharges himself from hospital in order to pursue an artistic life. The novel is also about 'dismemberment,' and refers to the myth of Orpheus: 'Orpheus is torn limb from limb, The last thing was his head, going down river singing and searching for his body parts, so that, having been dismembered, he can re-member himself.' This is what William did: he crafted a new self. 'I went through my life: do I need this? No: chuck it out; yes, this is important. I remodelled myself, separated myself from some powerful influence in my younger life, put myself together in a way that was more pleasing to me than before.' William said we can become better at being ourselves, and in his particular example he relates this capacity to narrative thinking. Again, it was a story that kept him from the dangers of nostalgia. In a Welsh myth, a golden bowl fills with memories the heads of all those who try to hold it, and keeps them frozen to itself. William, when bedridden for three months, could have fallen into the trap of memory: he had had an easy life, and had lots of happy memories. But he realised the danger of drowning in nostalgia. He also learnt something from another passage of the same myth. A mist filled the landscape that the characters were contemplating, and when they awoke the next morning, the scenery had completely changed. William used this as a metaphor for his sight loss. He related the characters' trying different trades to make a living to his own professional soul-searching after sight loss. This search came to a positive end at a storytelling club, where his wife volunteered to go onstage and tell a story in order to set an example for him. The following month, he had gathered the courage to go onstage himself, and that set the wheels of his career in motion. He eventually became self-employed, after having been without work for seven years. As mentioned above, William says this 'absolved [him] from the pressure of having a successful graduate career':

It didn't matter that I was not trained as a lawyer. How can I? I am blind. Didn't matter if I didn't have a proper job. How can I? I'm blind. That's a get-out-of-jail-free card. That is such a gift. And then I have the gift of spending the time in the cave, the gift of isolation, the gift of incapacity. You can't control what life gives. I can't control my severe visual impairment, my nasty diagnosis with a very gloomy prognosis, but I can choose how to respond.

It took him a long time to train his voice, a process that he describes as incredibly hard. Equally hard was his adjustment to his visual impairment and to the spatial challenges it poses. William used walking as a method both to learn to navigate space in a different way and to memorise his stories, which he did during his strolls. William took me on a walk in the park in his local area, where he has been living for five years. As he used the tall buildings as landmarks, I warned him of the puddles and branches on the ground. Where minuscule hassles get in the way, magnitude is used as a compass. 'This park is so thin. For a long time I was not familiar with it, because I didn't know it was this thin.' William had not been to this park before he bought his house, and when he started frequenting it he became familiar with the path, but not with the shape of the park, because he could not see as far as its perimeter. This sense of disorientation extended to the whole neighbourhood. 'For a long, long time the only existence I knew of was the house I've just showed you [his house], the local underground station, and this bus stop. Then sometimes I'd go by underground from [one local stop to the next], but I had no idea about how to connect the two places.' In some case, it took him years to fill the gap.

Even something as small as this is daunting because once you are in a place where you don't know where you are, you don't know where you are gonna end up. Or how to. You don't know how to go from that state of unknowing to that state of knowing. It took me a long time to get to know this park. You try and repeat a walk, it goes wrong, you find yourself somewhere else, you try and remember it, but you probably don't. Now I'm here because I chose to be here. When you know where you are, when you know how things are related, you can make a deliberate decision to walk from here to here to here to here. Before that, it's pure chaos.

Independence, so cherished by many of my participants, has a strong link to orientation, in William's mind: 'If you know where you are, if you know where people are, and things are, you can choose, you can make a conscious decision to choose. If you can't, you are purely the passive recipient of people's information and generosity.' This feeling manifests itself at different scales. As far as a smaller scale is concerned, William lets us peek into his social life by shedding light on interpersonal dynamics that may be overlooked by a careless observer:

> *When I go to a bar, filled with people, I can't find my friends. They are there, but I can't walk across the room and start a conversation. I can't say: 'Oh, they look interesting,' or: 'They are looking at me in a friendly way.' That doesn't exist. And I can't recognise people across the table, if they don't make a sound. If I don't really know they are there. When I go to a bar, I just wait there and see who comes up and talks to me. And that's the opposite of who I used to be.*

At a larger scale, being unable to find his way in his own area makes William feel 'humiliated by his incapacity.' He says he makes 'idiotic mistakes' when trying to orient himself, and even recalls wasting 40 minutes trying to locate his house, until he eventually swallowed his pride and phoned a family member for help. The role that orientation played in his sense of dwelling is something he emphasised to me in an email written shorty after one of our walks:

> *What I said to you about slowly expanding my awareness of my surroundings after I moved is, to me, important. It was only after I'd begun to build for myself a mental simulation of my new area, enabling me to think of places in relation to other places and not just monads, that I began to feel 'home.'*

Now that he has familiarised himself with his local park, William often visits it if he is doing a 'thinking walk,' a walk that allows his feet to walk without concentrating, so that he can think about something else.

> *The fact that your body is occupied is a way of stilling your mind, it helps with concentration. Funnily enough, people write about this now: how much*

thought can be done at three miles an hour. Think about pilgrimage! You think about the changes you want to make in your life, the experience you want to have when you get to the holy place, when you walk back. You think about your life, what you are gonna do when you go back to it, how you are gonna integrate those changes into your life.

William himself, as described above, had to rethink his professional life after he lost his sight. Indeed, independence to him has a strong connection with orientation, but also with being active professionally: 'I can feed myself, I can wash myself, I can clothe myself, I can get around.' He praises the transport system in his city, which is friendly to visually impaired people. 'I can go to the shops, I can buy food, etc. I earn money. I am one of that minority of blind people who actually works.'

Just like developing his orientation through walking made William feel at home in his new neighbourhood, so walking helped him develop a repertoire of stories for his new job. He used to walk on a quiet path along a canal (with earphones on, so that if people saw him talking on his own they did not think he was mad) and practice his stories. 'Working, working, working,' that's all he did at the time, until the stories became engrained in him. Many years on, William has not got his sight back. For a very long time, he hoped he would, as some people with his condition do. However, he calls himself happy with what he has achieved, both personally and professionally. His stories have become part of him and, as he shares them with his audience, they become part of them. Oblivious to the sexual, the macabre, and the exotic, they listen on, as he takes them on a journey just a bit shorter than his own.

Chapter 6. Emplotting the Self in Order to Transform Others

6.1 Introduction

In a short autobiographical paper on her experience of living with multiple sclerosis, Louise Duval argues that disability may serve as a lens to look at what it means to be human (1994:4), which is the ethos of anthropology as a discipline. She also touches upon various topics that are also discussed in this thesis: the individuality of the experience of living with a particular disease (ibid:3); the moving in, as well as out, of the category of disability (ibid.); the distress of having to give up one's professional commitments (ibid:4); and the 'compassion' and 'intimacy' felt in the disability community (ibid.). She also makes two related arguments that are at the heart of this thesis. The first one, which has been described throughout this work, is that the complex situations that disability gives rise to may not be obliterated, as they may open up more choices for the sufferer (ibid:5). The second one is that this can happen by sharing with others one's story of living with an impairment (ibid.). This point is the main topic of this chapter, where I observe that, besides the relationship between old and new self, one thing that makes my participants' lives more firmly emplotted in the long term is their capacity to inspire others through their own stories. I develop the theory of therapeutic emplotment and suggest, firstly, that it can be a model in the sense described by Richard Sennett (2006:101-103). A craftsman creates something not in order to be copied, but in order to encourage other artisans to create something that is the fruit of their own creativity. Similarly, my participants aspired not to be imitated indiscriminately, but to trigger in others a similar desire for self-transformation. Listening to visually impaired people's stories may inspire my informants' interlocutors to emplot their own lives therapeutically. By positively reframing their own lives their interlocutors may, in their turn, inspire others. Secondly, I put forward the idea that therapeutic emplotment can be co-constructed: by seeing the benefits that the stories they shared have on others, my informants may realise the potential they have to transform other people's lives in a

positive way[44]. In the previous chapter I introduced the notion of therapeutic emplotment as a moral compass by presenting the metaphor of a portrait, which would morally elevate the sitter-become-viewer. In this chapter I would like to use the same metaphor to explore the notion of co-constructed-ness. The portrait served as a tool to orient the sitter not only because it depicted him without flaws or contradictions, but also because its surface preserved the genius of the master who painted it. Similarly, for a person who meaningfully communicates her story to others and who, crucially, realises the positive changes she brings about in others and incorporates them into her own life narrative, therapeutic emplotment is less prone to disruption, and its effects may potentially last in the long term.

6.2 Therapeutic Emplotment between Old Self and New Self

In this thesis, I have given multiple examples of the benefits that my participants derive from narratively restructuring their lives. However, to expand on what was said in chapter 5, therapeutic emplotment is also fragile. Since after reaching a new equilibrium there may be further disruption, the balance attained after a successful therapeutic emplotment is always hanging by a thread. According to Cheryl Mattingly, narrative time is marked not by stability but by change, or by the attempt at change (1998a:94). To see oneself in a story means not striving towards a fixed ending, but seeing one's 'life in time as stretching out towards possibilities, both hopeful and fearful, which [one has] some influence in bringing about' (ibid:92). Sometimes actors may decide that 'an ending is not so desirable after all' (ibid:93), and direct their energy to a new objective. Moreover, 'actions may be the central cause within narrative structure, but their causal efficacy is anything but sure. Nothing is guaranteed in the realm of human action' (ibid:95).

What can disrupt therapeutic emplotment? On the other hand, through what temporal strategies of connection to or rupture with one's past can therapeutic

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[44] Cfr the 'helper therapy principle' formulated within psychology. Helpers, rather than those being helped, can benefit from their activity (Riessman 1965) and, as a consequence of that, they can become increasingly better helpers (ibid:27).

emplotment be made resilient? I will deal with these two questions in turn. The stability of therapeutic emplotment is, as Mattingly suggests, under the influence of many more variables than mere personal agency. This is supported by ethnographic findings. For instance, emplotting one's life therapeutically is difficult when, in addition to a particular diagnosis, an individual is confronted with the disappearance of most of their social circle because of the same disease (Bloom 1997:459-461). In the case of lives perturbed by past traumatic events, there may be only fragmentary memories (Williksen 2004:125) around which to build the narrative of a life that was never agentically '*lived,*' but only '*suffered*' through (ibid:126, original emphasis).

I personally found that my participants, who were both congenitally and adventitiously visually impaired, were confronted with a number of factors that destabilised the balance they had achieved in their lives after the crisis caused by sight loss. A different life phase, for instance the transition from education to employment, may require them to adjust to a new physical and social environment. Historical changes in the socio-cultural context may cause a similar need for adjustments. Some of my informants were old enough to remember an RNIB that they defined as 'Dickensian.' The series of names that the organisation has had since its foundation in 1868 reflects the societal transformation that has occurred in Britain during the last century and a half. For instance, in 2002, when the RNIB became a membership organisation, it chose a new name: 'the Royal National Institute *of* — not *for* — the Blind' (RNIB n.d.c). Six years later, 'the blind' was changed to the less stigmatising 'blind people', and the strapline 'supporting blind and partially sighted people' was adopted (ibid.). One of my older informants once told me that the RNIB in the past was not interested in partially sighted people, and indeed these individuals were recognised as falling within the remit of this organisation only 140 years after its foundation. Some of my participants also remembered a public attitude towards disability that was much less respectful. As a consequence of this attitude, Andy, who grew up in the 1960s, admitted finding it hard to shed the label of 'cripple' from himself, as we saw in the previous chapter. He therefore had to constantly reinstate his desired persona within himself. The result of a successful therapeutic emplotment could be undermined not only by cultural factors, but also by physical ones, notably eyesight, which can change in quality or degree over the course of a lifetime.

The relationship between the old and the new self is central in therapeutically emplotting one's life in an effective way, and in producing a life narrative that can function as a moral compass. In this relationship, continuity and change both play a role. This has been evident in the stories of my own informants that I have presented, and I will expand on this after giving some ethnographic examples from medical anthropology of the role of continuity and change. As far as continuity is concerned, Arthur Frank argues that 'the repair begins by taking stock of what survives the storm' (1995:54), and 'the self is not so newly discovered as newly *connected* to its own memory' (ibid:129, original emphasis). Sometimes a connection to the old self is enabled by the progress of biomedical sciences, which allows people whose prognosis in the past would have been poor to envisage future selves. These future selves emerge out of the past of the particular person. As a way to 'colonise the future' (ibid:228), a transplant can offer a patient a chance to realign his narrative with an intense work life sustained well into the onset of illness (ibid:224-225), as well as with that of an ableist cultural norm (ibid:227). In this case, the cultural embeddedness of emplotment is important: in a context where productivity is a value, a risky lung transplant can be preferred over a more limited lifestyle (Maynard 2006). The theme of cultural embeddedness is also present in Bergstresser's ethnography. As explained in chapter 3, she observes that, among the people with mental illness she studied, only those with a lower level of education found that working on a farm gave them dignity (2006:15). Those with an academic degree considered it demeaning (ibid:17-18). It can be noticed, however, that in both cases there was continuity between the self before and the one after the onset of mental illness. Her informants' past professional identities influenced how they emplotted their new professional selves, and those who had attended university wished to secure a job worthy of their academic training.

As Bergstresser's work indicates, connecting to one's old self may be a double-edged sword. This happens also when the element disrupting one's life course is the failed accomplishment of a particular life stage, such as reproduction. Considered by some as the culmination of the mature phase of one's life, it throws the present self into chaos and compromises its future development (Becker 1994:383). Among the numerous metaphors used to describe infertility is one that is also used by some

adventitiously visually impaired people to define their sight loss, i.e. death (ibid:384, 392-393, 395-396). When those affected by infertility manage to reconstruct their sense of self, they do so against the cultural assumption that producing offspring is a natural life stage (ibid:391). Reframing one's situation within this cultural model is a difficult (ibid:402) and, if infertility persists in the long term, lengthy process (ibid:398). In fact, infertile individuals are seen as at odds with the shared cultural assumption that lives are continuous (ibid:384, 390).

If it is true that continuity with one's old self may be more or less be therapeutic, narrative disruptions may also help individuals clarify how they came to their present situation and give them new impetus to move forward. Breaking away from one's past life is, for instance, claimed to be essential to some forms of religious conversion and belonging (see Brahinsky 2013, Daswani 2013). More relevant to this research is Vanthuyne's study of people with mental illness in Quebec (2003). She identifies the different narrative types they use: while one of them is a narrative of continuity (ibid:419-420), another one revolves around the life transformation brought about by the onset of mental illness (ibid:415). Although the author hypothesises the existence of narratives in which discontinuity is emplotted by the person as a turn for the worse (ibid:422), in her research she finds mainly evidence of the opposite. For instance, one informant describes himself as having 'evolved' in a positive way since he was younger (ibid:421).

In regard to my own participants, I argue that continuity and change were mutually sustaining in their process of emplotment. During my fieldwork I found that, on the one hand, the emplotted self was made out of the same clay that gave shape to the old self. When aiming to project themselves onto the future, many of my informants had made the effort to reconnect to their past. It was as if the way for them to overcome the crisis triggered by sight loss was to realise that they were not facing a blank canvas; that they did not have to recreate their lives entirely anew. On the other hand, in many of them sight loss triggered a personal change for the better. This coexistence of continuity and change is exemplified by Andy, who, as we saw in chapter 5, after he lost his sight compiled a list of what he, thanks to his previous experience, could do, and of what he had always enjoyed doing. This allowed him to fill his days, which had suddenly become totally empty because of medical

retirement. Importantly, he found a new career in psychotherapy based both on his old skills and on those he developed anew, as well as a new way of engaging in old hobbies such as the theatre. In sum, after sight loss he discovered 'new possibilities' (Vanthuyne 2003:421), very much like the mental health patients in Vanthuyne's study, who reframed their self in a more meaningful way through narratives of discontinuity.

Vanthuyne also observes that her participants moved between different narrative frameworks, which confirms the complex, non-exclusive role that continuity and change play in people's therapeutic emplotment. Here I suggest that, on the one hand, emplotment is never stable but, like the life structured as narrative described by Mattingly, is punctuated by moments of suspense (1998a:157). Therefore, the continuity between the self before and the one after sight loss may provide visually impaired people, as well as other people with disabilities, with stability. This stability is much needed when facing the challenge to withstand the setbacks that are likely to happen again in the future. On the other hand, emplotment feeds on possibilities for new horizons, which may emerge also through disruptive events such as the onset of a disability.

6.3 Therapeutic Emplotment as Model, and Co-construction of Therapeutic Emplotment

I have so far shown how important therapeutic emplotment is to confront the distress caused by sight loss. I have also shown that the new self that is created through this process is fragile, and is therefore always in the making. In this section I contend that therapeutic emplotment acts as a model for others and is co-constructed, because it is buttressed by a type of personal betterment that is developed through mutually enriching interactions with others. As people with sight loss share with others their own transformation, they may transmit to them a desire for self-improvement. Such desire may act as a proof of the positive changes that the visually impaired person may bring about in others, and create a positive feedback loop.

In anthropology, a narrative and its teller are never analysed in isolation. Rather, the people relevant to the narrator's past and present worlds inevitably emerge. This happens even when the focus of the study is the power of narrative to encourage reflexivity, for instance on one's professional practice (see Wood 2000). Moreover, anthropologists have looked at the space between narrator and listener, or on the space between two different narratives or multiple narratives. For instance, anthropologists have described the interplay between community and personal stories, and the potent influence the former can have on the latter (Humphreys 2000). They have also presented narrative as co-constructed 'through the act of being heard' (Lovell 1997:362), i.e. by both teller and listener, and argued that narratives in certain cultural settings are dialogical (Mannheim & Van Vleet 1998). Anthropologists have also shown how individuals can adopt institutional, for instance corporate narratives (Linde 2000), how they can create new self-narratives when joining a new professional setting (Eisenhart 1995), and how narratives can be used as a 'technology of the self' (Dunn 2014) or as an alternative form of evidence in a court of law (Cruikshank 1998:63-64). One ethnographic example that is particularly informative is the one of the Kayabi of Brazil described by Suzanne Oakdale (2002). She realised that, while some songs performed during Jowosi rituals were autobiographical and others were considered to have been inherited from a member of the previous generation, some songs were both autobiographical and inherited (ibid:160). Through these songs the singer could, for instance by using the pronoun 'I' (ibid:169), talk about his experiences by singing verses that had been composed by a father or an uncle about his own vicissitudes (ibid:167). This mimicry is intergenerational (ibid:170) and aims at the development of the younger generation (ibid.). In my own material, speaking of mimicry would be inaccurate because the recipient of the tale has the freedom to use it as a model (Sennett 2006:103) rather than an injunction (see chapter 7). However, Oakdale's ethnography creates an interesting dialogue with mine because she describes stories having an effect across generations, whereas I describe the power of stories exchanged among contemporaries. The way in which I would like to contribute to the vast and heterogeneous literature just outlined is by showing how my participants' narratives effected changes in their interlocutors and how this process contributed to the therapeutic effects of their hard-won emplotment.

My informants had different ways of sharing their stories of successful, though precarious, therapeutic emplotment. In fact, in this thesis I have presented them in a *crescendo*. I started by discussing how people, in particular users at Sunshine, started their recovery from the shock of sight loss by joining a VI group. Theirs was the most subdued way of conveying their story of recovery to others, as they were still too engrossed in themselves and the small and big challenges they faced to share fully formed narratives. They simply demonstrated that, after a period of isolation, they were ready to step out of their homes and challenge themselves by engaging in old or new hobbies. At a higher level of engagement with others, workers at Spring showed through their long journeys to the factory that, in the face of visual impairment or even multiple disabilities and afflictions, it was important for them to be active participants in society. Again, this was done away from the limelight, indeed in a factory that, no matter how involved in self-promotion, is not a mainstream employer. Demonstrating a much deeper level of engagement with his interlocutors, William relied on a vast repertoire of stories not limited to his own in order, if not to transform, then to raise people's awareness of the intricacies that pervade life. He also, indirectly, showed how he had become professionally active following the onset of (and, to a degree, thanks to) his disability. Yussef, whose portrait I will include in this chapter, attempted to do the same through public speaking in an even more overt way: he often tried to produce a positive change in others by using his own personal life story as an example.

Regardless of the particular depth of their engagement with their interlocutors, for many of my participants sharing their stories went hand in hand with raising awareness of disability. This happened in a spirit consonant with what disabled academic Devva Kasnitz calls 'disability exposure', i.e. by helping members of the public get into contact with disabled people and, as a consequence of that, recognise the person behind the disability and her special knowledge as a disabled person (2020). For instance, Stella was keen on giving people in business and the general public a practical experience of what it meant to live without or with little sight. She organised training programmes as part of which participants had to play tennis while wearing different types of simulation spectacles, i.e. glasses partly blackened in order to simulate the field of vision caused by particular eye conditions. Participants could also learn to read basic Braille and try to pour water into a cup or guess the

type of food they were eating without looking. In spite of her enthusiasm, Stella was quite matter-of-fact about what one could learn through these exercises: 'My condition is pretty rare, they don't have glasses for it. 'Cause if they were to do simulation glasses like that, that would give everybody a headache.' Still, she tried to compensate for the limited expected outcome of the programme by integrating into it Q&A sessions and discussions on what sighted participants thought a visually impaired person could or could not do. Outside of the framework of these workshops, similar discussions acquired a particular salience when the person she taught was an adventitiously blind person: Stella had also taken the initiative to give a friend who had recently lost her sight the confidence to use public transport. Another of my research participants, Olivia, who has extensive professional experience in special needs education, set up disability awareness programmes in schools for both children and teachers. Her ethos was to encourage people to give weight to what visually impaired individuals could still do over what they were no longer able to do. She approached local businesses for the same purpose, which allowed these companies to realise how inadequate were the provisions they offered to disabled people, especially young disabled people entering the workforce. Gemma, a dynamic middle-aged woman who was working part-time during the time of my fieldwork, had the idea of organising a disability awareness training for her colleagues. Motivated by the thought that having her in the office might be perceived as 'a pain' by people wrongly assuming they would have to completely rearrange the workspace, she was determined to make the experience 'fun.' She brought in all her talking devices: her talking phone, her talking clock, her talking weighing machine, as well as her canes. She also made all staff members close their eyes, she chose one person who should say 'hello,' and she made everybody guess who had spoken. The game proved amazingly hard. Gemma also taught them practical skills, such as how to guide her and show her a seat. Like Stella, she gave them the opportunity to ask questions and made the session interactive. This was the only time when she had trained someone 'in an official capacity, rather than just friends.' In Gemma's own family, the informal training on how to accommodate to the needs of a visually impaired person was so ingrained that her young children usually played tricks on her taking advantage of her inability to see them. Gemma, who hates being 'treated special,' welcomed these playful interactions. Curiously, her children were apprehensive when the family hosted another visually impaired person: they were so

used to interacting with their mother that they did not think of her as blind, which made them believe that they would be unprepared to deal with another visually impaired person.

As it appears from these anecdotes, for friends and family members constant 'learning-by-doing' usually replaced formal training. Regardless of whether training was formal or informal, though, visually impaired people attributed a certain importance to this rather mundane, non-ideological pedagogy. Indeed, they saw it as an antidote to the 'work' of 'explaining themselves,' which I discussed in chapter 2. 'People treat you differently through ignorance,' told me a participant, who recognised that malice was rarely the cause of discrimination. It is evident that dispelling such ignorance was an important mission that my informants carried out as a necessary first step towards achieving more inclusion in society, as well as a smoother daily life for themselves. The mundane nature of all the anecdotes described above should not mask the fact that these situations were part and parcel of emplotment. Although, as the events happened, they were not verbally articulated tales, they were 'moral laboratories' (Mattingly 2014) that afforded my participants opportunities to redraw their own position as people with sight loss in their immediate social circles. Besides, the fact that my participants recalled such events at a later stage in our conversations did give to such incidents a narrative quality and a particular salience. Again, the creation of stories by my informants did not happen in isolation, but with the aim of reaching out to others, whose positive transformation may help them cement their own therapeutic emplotment.

In this process, professional work played an important role. My participants' aspiration for bringing about change in the social world surrounding them was connected to their wish to become better at being themselves, as William phrased it. This betterment, as I anticipated in chapter 5, happened also through 'welcoming back' (Watermeyer 2009:100) sight loss as an 'enrichment of life' (ibid:97). What instances of betterment were presented by my interlocutors, and what commonalities can be found among them? I noticed that many instances clustered around the professional domain. For those among them who had been lucky enough to make a satisfactory professional transition, their new job was a particularly important 'enrichment of life.' In fact, it benefitted not only them, but also the people they

interacted with in a professional capacity, which supports the idea that therapeutic emplotment can function as a model for others and be co-constructed. William could break the mould that had been cast for him as a graduate of a prestigious university, and explore something different, which came to benefit himself and, ultimately, his audiences. Whereas for him, who then did not have a proper job, sight loss opened up the gate to a career tailored to his skills and personality, for participants for whom sight loss entailed job loss the crisis brought about by visual impairment triggered the search for a more fulfilling career. This happened because they were no longer tied to their professional role, nor to the status that it conferred upon them. For instance, after a period of training for a new professional qualification Andy moved from a high-pressure work environment to a speech-based job, psychotherapy, which was intrinsically more humane. Moreover, he considered his visual impairment to be an asset in the particular setting of his new role because he thought that it allowed him to give his clients the absolute certainty that they would be judged on what they genuinely were, not on their visual appearance. In sum, for some of my informants the narrative 'work' of meaningfully reframing their lives dovetailed with the meaningful reframing of the type of work proper they did. The professional arena was one more area where visual impairment was incorporated into, rather than rejected from, their lives. It was also a further opportunity to communicate to others, more or less directly, the positivity of their newly emplotted lives.

6.4 Losing Sight without Losing Vision: Portrait of Yussef

The same visually impaired people who find indifference if not hostility in the crowds of Donchester sometimes find themselves put before others: do they need a seat on the underground? Would they like help with crossing the road? It might be difficult to find opportunities to be helpful when altruism always seems to be directed to you. I have these thoughts in my mind when I think back to the time when, in a difficult and precarious period of his life, Yussef still made time to be interviewed. With him, I spent the most carefree and cheerful moments of my fieldwork, but also the most poignant ones, as we took the time to expand on the meaning of visual impairment in his life. In both cases, however, he invariably made sure that *my* needs were met. Was I tired, after picking up countless tennis balls during his blind tennis practice?

Was there anything else I wanted him to expand on? For Yussef, believing and living are one and the same; his values guide him and, through them, he endeavours to guide others.

In this section, I present the portrait of Yussef. The portrait also contains references to important topics that have been dealt with throughout the thesis, such as the eventual acceptance of blindness (in this case symbolised by the white cane), the incorporation of visual impairment into one's life narrative, and the pivotal role of work in it. More importantly, if the stories of the participants described in chapter 2 were shared *sotto voce*, Yussef shares his own in a *fortissimo*: he explicitly uses his own life story as a public speaker to instil change in others. Nevertheless, he does so in a non-prescriptive way, very much in line with Sennett's notions of 'craftsmanship' and 'model.' The portrait of Yussef is actually a meta-portrait: just as he presents himself as an exemplar, I present my own rendering of his presentation. Since my depiction of Yussef is textual rather than pictorial, it is fully available to him, which paves the way for the overcoming of the sighted/sightless divide dealt with in the concluding chapter.

'I have lost my sight, but I have not lost my vision.' This is one of the maxims that Yussef lays great emphasis on during his public talks, as well as something he lives by:

> *That is honestly my main motivation to deliver talks: to make other people's lives easier, to show them that they can also do it. And I think if you can make someone's day better, if you can give someone hope, if you can save one life by saving them from committing suicide, I think that's a huge success.*

Yussef, who is in his mid-twenties, is originally from Asia and came to the UK in order to do his master's. After completing it, he started working for the company where he is still employed. Alongside his job, he takes a keen interest in sports and public speaking. He tells me how he got into public speaking:

> *When I was young I lacked a lot of confidence, because I was the only blind student in my school. Kids tend to be very non-politically correct; they do not*

care about what they are saying, how they are behaving. So I think that
affected me: I lacked the confidence to do things on my own, to talk to people,
and I do not know if that was the reason, but I started to stutter severely. It
became more severe when I grew older. When I was five or six I think that's
when my mum decided to take some sort of action and make me narrate
stories to her.

Yussef continued to give talks written by members of his family, until he gave one, written by his aunt, at his school farewell party. That made his teachers cry. He had attended that school for thirteen years, and was the only blind student. After that, he took a more personal interest in public speaking and, encouraged by his father, joined Toastmasters International, an international community of public speakers. One of the first talks he penned himself was his introductory speech as a member of the organisation, in which he spoke about the story of his life. Eight years on, he has appeared in front of different audiences in various countries to talk about various topics, but he still maintains a penchant for autobiographical talks. This gives him the opportunity to discuss disability, attitudes towards disabled people, hope and spirituality, which are all themes he feels strongly about. These themes were woven into the talk he gave to an audience of 1000 people, which he considers as the peak of his trajectory as a public speaker.

Could he have conveyed the same message in writing instead?

Public speaking for me makes it more real, because you are really hearing the
person, instead of reading something that they have just written. It is
something light, where I get to meet people directly, something that I can tailor
to my audience. With reading sometimes you can't do that.

Yussef, like various other visually impaired people described in this thesis, is keen on leading by example:

I'd share my experiences not only to advocate for people with disabilities, but
also to make disabled people aware of what they can do, and that is
something that almost every talk of mine touches upon. We all know things

like: 'You have to struggle hard to succeed, you have to manage your time,
you have to have a positive attitude,' I think every single person knows that.
But when you see a living example of that, and you see how that person
achieved that, you see the way they deliver it, then that's what resonates with
people. I don't think I have ever been to any motivational speech where I have
heard something when I go like: 'Oh my God, I never knew this before.' But
when you see a living example of that, then that's what resonates with people.

Yussef may emphasise the speakers' presence rather than the content of their talk. Still, his story is far from ordinary. After listening to it, the mother of a twelve-year old approached him: 'You've helped my son get some sort of direction, helped motivate him.' She is not the only one who has been touched by Yussef's vicissitudes. When Yussef was born to a Muslim couple in Asia, he had a visible but unexplained eye condition. Yet, his parents 'took [him] home,' metaphorically as well as physically, and thanked God for the blessing of their first child. 'They decided to embrace the challenge and raised me up like a normal child, so in many ways my upbringing was very normal, very good,' says Yussef. At the age of seven, Yussef turned from partially sighted to completely blind. 'I can't remember a day when I woke up and I could not see. So it's primarily something pretty gradual. And something that, maybe for good, God removed from my memory.' Much later, doctors found that he had a congenital ophthalmological condition. Looking back, Yussef says that having been accepted by his family makes him feel 'more privileged,' as he is aware that lots of babies that were in his similar situation were abandoned.

He describes finding it hard to accept his blindness. 'I used to be a very angry young boy, probably because of this [blindness]. But I think lots of my acceptance was done for me by my parents, who gave me the confidence that: "No, you *can* do it". *They* had to do a lot of work, not me.' Yussef's mother used to tell him the story of Helen Keller when he was little, which has inspired him — end enriched his speeches — ever since:

Even when you read Helen Keller's book, you realise she used to be really
angry. I think coming to terms is not just one button that you press. I think any
problem that someone has, one has to constantly accept it, and constantly,

and constantly reinforce that acceptance. Because it comes back in different forms to haunt you. To make you realise that lack that you have.

He says family has played 'a huge role in who he is today, as has religion:

Religion has always played an important role in my life, from the very beginning, because I was born in a… I won't say particularly religious family, but in one that was observant to a certain degree, and religion was quite pronounced in the family and in the society as well, so that is something that I grew up with.

Yussef's family helped him develop not only the spiritual facet of his life. 'My mum focussed a lot on my education, and wanted to make sure that I do well at school, prove my worth to the other people.' She read Shakespeare's *Macbeth* to him when he was only seven. 'My dad, on the other hand, was more about making me have fun, making me try the wonderful things around me: sports, public speaking, going out and partying in a good way.'

Just as his parents were keen on showing him that he could embrace different opportunities like any normal child, Yussef is keen on showing, with his public speaking, what can be achieved by someone without sight. He describes how, step by step throughout his life, he changed people's perspectives of his capabilities:

When I applied for my undergraduate they first refused me for engineering because they just said I couldn't do it, then I convinced them: 'At least give me one more chance, don't just dismiss me.' And they let me meet the dean, who took an impromptu test, I had no preparation, nothing at all, and he sounded quite impressed because obviously he asked me technical questions that I was able to answer, and he said: 'Let me go back and discuss with my board,' and obviously the answer was affirmative, which is why I was able to study there. So that was just one example, but there's so many people that have either become more willing to explore something, for example my tutors, or people that I have met in interviews, or in social groups, where their opinions have changed. They go like: 'It's quite nice to see what people with disabilities

are able to achieve and how they do it.' 'Cause they don't know how it is possible. Like, when I tell people about blind tennis, they go like: 'How do you play tennis?' Once you explain it to them, it makes much more sense.

Yussef's journey towards the high level of independence he has today was not smooth, however. The incident of his admission to university described above took place in a foreign country, where he and his family were living. After he was admitted to university, he moved to the city where his university was located, 400 kilometres away from the city where his parents were living:

> *The saddest bit was when my father was saying goodbye to me, and going back to [other city], 'cause I just felt I was completely on my own, in a city where I didn't speak the language, where I wasn't sure how I'd cope, and actually didn't know how to use my cane, so I was pretty dependent on other people, so it was all of that coming together. I think I still remember my heart sinking. I used to go back to my family every weekend, 'cause I used to miss them, and that was the 1st time I had ever been away. Slowly I became more and more independent, more happy to be on my own, and my visits to my family reduced and, I guess, at the end of it, it was once a month, sometimes even less.*

Yussef feels his role in the family has never been diminished by his visual impairment. At the age of 18, when he was still living with his parents, his father emigrated for work reasons, so Yussef 'took the responsibility of waking up first,' and waking his mother and sister. Various members of his family now ask him for advice, and they did so even when he was in his teens. 'My opinion does matter in the house, which is good' he comments, giving the example of when, in the context of a family dispute, his grandfather gave him the final word on the decision of whether or not to attend an uncle's wedding. He was only fourteen at that time. Now that he is thinking of getting married, he foresees his responsibilities increasing in the coming years: 'My main responsibility would be to take care of the house financially, even though I doubt my parents would let me do it. But obviously in a couple of years they will have to retire, so my responsibility will be to try and keep the house ok

financially, resolve any kind of disputes or problem, try to maintain harmony in the family.'

When I ask him about how his blindness may impact his role in the family he will found, his answer focusses on the material side of life: 'I don't think it would, 'cause I think, despite my blindness, if I have a good job, which I hope I will, I can be financially sound and support my family, and I don't think if I was sighted my salary would be higher.' He also says that he would like to 'share almost all [his] tasks with [his] wife,' although he is realistic and says he will not drive, which he can't do, or cook, which he hates to do. Just as his parents treated him as a normal child, he would like his future wife to let him carry out many household chores, such as cutting vegetables. He thinks it is crucial to 'minimise the things that she has to do' for him, such as accessing some websites, and believes that he 'will be a much better husband than a lot of sighted people.' 'I won't be judging my wife in any way based on her looks, for example.' 'I can give back, I don't mean because of my blindness, but because of the person I am.' In sum Yussef seems himself as the product of his manifold life circumstances, which include, but are not limited to, blindness.

Reflecting on his personal path, Yussef draws on the most disparate sources to enrich his speeches, creating a special blend of entrepreneurialism and religion. Quoting Steve Jobs, he says that 'you can only connect the dots looking backwards,' and sees his life trajectory as led by the divine providence: 'Once you look back, I have loads of those instances in my life where I just feel that God was present at that time and was doing everything for my best interest.' He thinks that the suffering caused by his eye condition has 'definitely brought [him] closer to God.' 'All the things that I have been through have really shaped who I am as a person, and have definitely made me, I think, more empathetic, more positive, more compassionate to other people, maybe made me realise the value of life a lot more.' 'With every hardship comes ease,' and 'God never tests you more than what you can bear' act as pillars that sustain both his life, and that of the people he shares these phrases with, in words and through his example.

He does, however, recognise that living with blindness is also a daily battle. When I asked him what the life domains were in which blindness was most unbearable, he

mentioned mobility, and peoples' attitudes towards the abilities of disabled people. Nevertheless, he is a keen sportsman who has won various medals in blind tennis and completed various races. As part of his answer, he added: 'I guess when it comes to academics, yes, when it comes to engineering, when it comes to looking at diagrams.' And yet again, Yussef has chosen a discipline that makes extensive use of visual means of communication: he has, in fact, successfully completed a master's in engineering.

'It really takes someone who understands me to know how I understand diagrams, and there's not many around the world.' Yussef talks me through the convoluted process of grasping something that is purely visual, and yet essential to his academic career. Tools like embossing paper are helpful, but the intellectual and physical interaction with an experienced helper is crucial. 'I do prefer to study with someone that has some subject knowledge of this. I ask them to run my hand on the table and to give me an idea of what it [the diagram]'s like.' Sometimes, what challenges Yussef is not understanding things, but communicating them: 'If I have to do long divisions of polynomials, I do most of the computations in my head. I find it very challenging to write it on paper but, if I don't, I won't get the marks, 'cause they don't know how I did it. So I need to memorise how people write the steps down. Which is incredibly frustrating for me, 'cause it is just a waste of time.'

His desire to lead by example is fuelled by his realisation that not many visually impaired people are realising their potential, even when the material circumstances of their countries are favourable:

> Because I had never been to the West before and I had heard all those nice things about the West, about how progressive it is, and how accommodating it is for people with disabilities, I had had the impression that I had to struggle to do science and engineering because my countries weren't equipped with the right resources, and people in the UK, who have all of those resources at their disposal, would be pursuing things like that. But, when I came here, I was shocked that people don't actually do that, and till now I haven't met a single blind engineer or scientist, and I have been in touch with various organisations that deal with visual impairment. Never come across any in my

entire life. So it was disappointing to see that a lot of these people do not aim as high as I was hoping they would. That might be because they don't have the confidence, or it might be because there aren't enough resources as I thought, which is partly true.

Yussef has lived in Europe, the Middle-East, and on the Indian subcontinent, where his parents come from and where he grew up. In order to make a bigger impact with his talks, Yussef adapts them to the cultural background of his audiences. He once went to a blind school in India, where he had been invited to give a talk with his sister, who is also visually impaired. He met some students who thought they were blind because of something really bad that they or their parents had committed in their previous lives. 'I don't want them to believe that, 'cause that would just not act as an incentive for them to do anything' retorts Yussef. 'I don't like this defeatist attitude. When you tell kids those kinds of things, they might grow up with that philosophy, and that will lower their confidence, and make them feel less worthy.'

Yussef explains his view of the different explanatory models of blindness, and of the role that religion plays in them:

> *Atheists or agnostics do not attribute their sight loss to a divine force. In contrast, some theists do, although this is usually because of cultural rather than strictly religious reasons. No religion considers blindness as a punishment, although some might argue that they do based on cultural norms. People who, like me, believe in a compassionate God, think that it is a blessing. In my particular case, it allowed me to look beyond external beauty, and be receptive to the positivity of the world, to which people are sometimes metaphorically blind. I don't look at my blindness as a punishment, I look at it as a test, and I feel that it's a way for God to test me, and he knows I can do it, which is why he has put me through it, 'cause God does not test a soul more than it can bear. In a way it makes me feel privileged that he has considered me out of millions of people to take such a difficult test, 'cause not everyone would be able to do it. So I don't look at it as a punishment. And I think most people around me, including my family, don't look at it that way. I think we all look at it as a test, and a blessing that God has given me.*

Yussef contrasts the attitudes towards disability in the parts of the world he is familiar with:

> *I do feel in India or Pakistan, where people maybe are not so aware or appreciative of people with disabilities, they would look at me or any other person with disabilities in a more sympathetic manner, whereas here [in Europe] people are, I think, for the most part, at least aware to a certain degree, and would rather treat me with empathy or apathy in many cases.*

Yussef remembers reading in the Quran that 'People who are blind are not those who are blind in their eyes, but rather those who have a veil over their hearts.' He finds many instances of this metaphorical blindness in Western society:

> *There's a lot of ignorance in society, but as long as it is not deliberate, it's fine, as long as people try to learn more. But I think people have definitely become apathetic towards things that have to do with humane values, that are not important anymore. Being polite to other people, or appreciating other people's problems, trying to help other people, all of that has now become secondary.*

In Yussef's speech, the social blurs with the religious:

> *I think people have become blind in their hearts when it comes to searching for the truth, and just accepting a lot of things at face value and just completely turning that away from just trying to find the truth. Like religion, for example, just accepting: 'Ok, I'll just be an agnostic, 'cause I can't be bothered.'*

In his talks, he often talks about his world falling into darkness when, as a child, he lost all of the little sight he had. That darkness was metaphorical as well as physical, as he lacked hope, but now it is his metaphoric light that he shares with other people. He does so by drawing on various inspirational lives, as well as on his own:

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Well, obviously if you are trying to convey a message you can't always talk about your own life, you have to show people that it is only one example. Different people have been in different situations, reacted differently, but there are other underlying themes in the things they have done.

Yussef builds bridges between the cultures he is familiar with, for instance by sharing stories from the Shia Muslim tradition with Western audiences. He finds inspiration in the 'patience, steadfastness and resilience' of Imam Hussain:

His story plays a part in my life, so so so often. He embodies all the good traits that humans aspire to. When I think about what he went through it gives me a lot of comfort, it gives me a lot of purpose, a lot of tranquillity, to think: 'If this man can do it, with so much positivity, why can't I do 1% of that.' It doesn't just teach me the spiritual aspect, but also the worldly aspect of things: about valour, about chivalry, about honesty, about trustworthiness, about how to deal with people that hate you, and that are trying to kill you.

Moreover, Yussef has recently refreshed his memories of Helen Keller's determination, perseverance, but also of her zest for life, by reading her autobiography. 'The only thing worse than being blind is having sight but no vision,' 'Keep your face to the sun and the shadows will fall behind you': these are all lessons that he has learnt from her writings.

Yussef admits that, even though he is quite adapted to sight loss, having lived with it all his life, he sometimes has to fight back questions that come creeping into his mind: 'Why did this happen to me? Why do I have to work so much harder than other people? Why? This is so unfair, this should never have happened. If only I could see, I could have done this, and I could have done that…' What could he have done? 'Oh, many things: sports, driving, walking around, looking at things, doing engineering, reading stuff, looking at all the beautiful things around, so many things.' But, when pressed, he admits having done 'all the things I have mentioned.' He regrets not being able to see 'the universe. God's universe is magnificent and absolutely beautiful. Be it the nature, the plants, the trees, the stars, the moon, the people, the architecture, the landscape, the sea, the oceans, the birds, the animals' But, there

again, he doesn't feel deserted by beauty, which he can appreciate through the non-visual senses. 'Although I have lost my sight, I think I haven't lost my perception. There's different ways in which you can perceive the world, and I think for me it is primarily through feeling and hearing.' More importantly, he does not feel deserted by God, or by the manifestation of the divine beauty in the world and in human beings. 'I thank God many times in the day for all that he's giving me. Not just God, also his creation. If someone does a favour to me, or anything like that. Gratitude is an attitude. And I think part of acceptance is to be thankful, because when you are thankful it makes you more positive, it makes you feel more blessed.'

Yussef has a disconnection from purely aesthetic beauty that, to him, has moral overtones. He says that, although he regrets not remembering the faces of his loved ones, which he saw in his earliest years, he thinks 'it's nice in the sense that I don't have any concept of beauty and ugly. People tend to get so judgemental about others, start judging them on the basis of how they look and I just feel I am protected from that to an extent.' To him, a beautiful person is 'a person who is beautiful from the inside. Someone who has a beautiful heart, someone who is kind, compassionate, generous, whatever good qualities they have.' Conversely, he trusts that, even though he tries 'to be neat and tidy' ('in terms of having my hair done properly, or make sure that I shave, making sure that I just look neat, and if it is a special occasion to choose the right combination of clothes: my suit, my tie') his 'true friends will go much beyond the physical looks and go much deeper than that.'

Conversely, he is grateful to be spared the visual manifestation of evil: 'I am sure people find a lot of angry people walking on the street. I luckily don't have to see that, so I just continue my day without being affected by those stares, by those angry faces. Maybe not being able to see is quite good, as it [the bad stares] can affect your day.' Ultimately, when asked whether he would like to see again, his answer is complex, but pervaded by his strong moral principles, in particular his wish to be an example for others: 'I can't say that for sure. I can't give a yes or a no, sometimes I do wish I could, sometimes I am quite happy with my life. I mean, I usually feel quite happy with my life. I think it [sight loss] has allowed me to give a lot more meaning to my life, meet some wonderful people, perceive things differently. Hopefully carve a path for other people that may wanna follow the same trail.' Yussef is relieved by the

impact he has been able to make so far: 'I know for a fact, 'cause I have met many people, that people's opinion have changed after I have told them the kind of things that I have been able to do, and have done. And hopefully, if we have more and more people with diverse experience, it will present a more holistic and accurate picture to society of people with disabilities.'

6.5 Stories between Teller and Listener

Yussef's story is the most explicit example of how my participants shared their therapeutically emplotted lives in order to effect a change in others. While above I concentrated on my informants themselves, in the concluding part of this chapter I would like to shed light on those who listened to their stories. In Yussef's portrait we saw him slowly overcoming his lack of confidence in speaking in public, gradually coming to terms with his sight loss and, finally, overcoming this very 'overcoming phase': he came to see his disability as a blessing to himself and others. Yussef may be seen as a hero, triumphing against adversity during specific moments of his life, such as when he strove to be admitted to that particular course at university, and also throughout his life. If we wish to regard him as a hero, we should also acknowledge that he was a hero feeding on other heroes' stories, and therefore had been himself in the position of a listener. He drew inspiration from figures such as Helen Keller. He also benefitted from the fortitude of his family and, at first begrudgingly, followed their advice on how to accommodate to his sight loss. The giving back to others was the direct consequence of his successful therapeutic emplotment and, more importantly, constituted the highlight of his success. 'The myths of failure touch us with the tragedy of life, but those of success only with their own incredibility' (Campbell 2008[1949]:178). I would argue that the resonance between the transmitter and the recipient of a story is what helps the latter supersede their incredibility in the story of the former. When Yussef's audience see him as a common person with challenges rather than as a wonder, they are also more inclined to be transformed by his story. In other words, the common humanity between teller and listener and the receptiveness of the latter are mutually sustaining.

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Mythological heroes are known to have to venture into faraway, secluded places in order to bring back a boon to humanity (ibid:28). My participants' gift to others, on the contrary, comes into being as they are part of the world, rather than detached from it. As he reaches out to his listeners, Yussef is on a public stage, not on an unreachable pedestal. Should he fail to establish a connection to his audience, his stories would vanish into thin air, and perhaps compromise the therapeutically emplotted story of himself as an inspired inspirer that he has crafted. Such connection is sustained by, and helps sustain, the common humanity between Yussef and his interlocutors, between my participants and those with whom they interact. If it is true that myth and religion offered guidance to past generations, whereas present ones are at a loss for a sense of direction (ibid:87), personal stories can still aspire to acting as a model. The quotidian side of these stories is what makes them real, and I would argue that it is the quotidian side of Yussef's heroism that grips his listeners.

Yussef once recounted to me that, as he and a friend were engrossed in a conversation, his friend took out his phone and told him: 'Look at this'. Absorbed in his interaction with Yussef, she had completely forgotten that he was blind. Yussef was very pleased at this mistake, as it revealed that the connection his friend felt for him was genuinely motivated by their affinity and common interests. To this person, Yussef was not a blind friend, but just a friend. This is an apt anecdote to introduce the central theme of the final chapter: common humanity.

Chapter 7. Looking Forward: Common Humanity Beyond the Sighted/Sightless Divide

From Yussef's portrait, it is apparent that a therapeutically emplotted story functions as a model for others and that its therapeutic nature derives from the fact that it is co-constructed by teller and listener. As a researcher, I was implicated in this process. All of my participants shared their stories with me on multiple levels. People at Sunshine, by adapting to their new condition, spurred me to think about how my life would change if I were to lose my sight. By making me part of both their camaraderie and their individual painful stories, workers at Spring manifested their attachment to work, a value that, in different forms, was treasured by all of my informants. William delighted me with conversations that, in spite of their distressing content, felt more like storytelling events designed just for me than semi-structured interviews. If, in the portraits, my participants' voices sometimes blend with mine, it is because neither their emplotment nor my narrativization of their stories happened in isolation. If it is true that 'machines break down when they lose control, whereas people make discoveries' (Sennett 2009[2008]:113), then my participants shared with me the discoveries they had made throughout their life journeys: they had learnt to appreciate the benefits of being part of a visually impaired community, to be more tolerant and resilient and, more importantly, they had learnt to share with others the person they had become following therapeutic emplotment.

In this chapter, I will leave in the background the ethnography above in order to focus on the common humanity that characterises a type of therapeutic emplotment that is both a model for others and co-constructed. As I mentioned in chapter 1, my participants were discreet about the different types of effort they put into managing their practical life and social relations, and never labelled them as 'work'. Far from being boastful, they were craftsmen rather than masters (Sennett 2004[2003]:83-84), i.e. they shared their stories as models, rather than as commands (Sennett 2006:101). Furthermore, in spite of the competitive nature of some of the activities they undertook, for instance sports tournaments, through the unassuming sharing of their stories as models my informants also availed themselves of 'the right not to be

outstanding' (Deshen 1992:83).[45] A model is 'a proposal,' 'something people might use on their own terms' (Sennett 2006:103). Indeed, each of my interlocutors laid emphasis on the importance for members of the public to interact with more than one disabled person so as to gain a broader impression of disability. As explained in chapter 1, they stressed the fact that 'every visually impaired person is different.' The 'model' described by Sennett is an appropriate tool for this discussion also because it instills in others a desire 'not to imitate, but to innovate' (ibid:101). And innovating takes work, just as it takes work to ponder the meaning that an exemplar figure may have for one's life, as opposed to following a rule (Humphrey 1997). The burden of the work of having to emplot one's life shifts from the shoulders of the teller to those of the recipient of the model narrative.

Andrew Sanchez's notion of 'transformation' addresses the nexus between work and narrative and is particularly useful to understand why sharing model narratives is therapeutic for my participants. By 'transformation', Sanchez refers to 'the quality of effecting change upon the world' (2020:70). Just as Sennett emphasised the non-prescriptive nature of the model, Sanchez highlights the imagination required by the person who transforms, as they have to envisage how the product on which they are working will be used by the recipient (ibid.). It is the inventiveness exercised by his Indian informants, who turn scrap metal into new objects, that makes their work more fulfilling than that of a worker on an assembly line (ibid:80). Sanchez observes that his findings apply not only to the transformation of materials, but also to social change (ibid:88), which makes his analysis relevant to my argument. His ethnography can be compared to my fieldwork at Spring, where the lack if initiative the workers had was conducive to narratives of unemployment and negativity rather than aspiration. However, Sanchez's work resonates with all of my material: the way in which my participants shared their narratives as a model (in the Sennett's sense of the term) was underpinned by the fulfilment that came from transforming others. Had Yussef not hoped to encourage others to overcome their own obstacles, as well as their reservations towards people with sight loss, he would not have found any satisfaction in sharing his life story. Sanchez argues that the finished metal product, fruit of his informants' labour, acquires a particular type of value in the hands of its

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[45] Cfr 'To be allowed to be human means to be allowed to fail' (Bengt Nirje in Groce 2002:51).

recipient (ibid:87). Similarly, the transformation of someone's life story into a meaningful message for the listener comes from the listener's own capacity to appropriate the model narrative they receive. Below I describe how the challenges posed by the present pandemic complicate the human interactions that are a fertile ground for this work of transformation. Here, I lay the foundations for that discussion by looking at how the scope of the exchanges that my participants engaged in was limited to the local.

It is interesting to notice that one of the findings of my research was that, in spite of the 'global urgency' that characterises today's disability activism (Berghs et al. 2020:5), my participants seemed to have concerns that were more local than global. It is important to consider that I carried out research not with activists, but with people for whom dealing with their sight loss was a daily rather than an ideological endeavour. Yet, it may have been plausible to expect that the global debates had 'trickled down' to the lives of my participants. This did not seem to be the case. From a global perspective, disability as a topic of discussion has two prongs: the globalisation of disablism and different forms of discrimination, and the recognition that specific cultural settings influence how such phenomena manifest at a local level (Goodley 2017). My participants were silent on the former, which is probably why they did not generally comment on the latter either.

Scholars have described the power exerted by international funding organisations in the Global South, which affects the agency of local activists (see Nett 2021). What is the perspective of activists in the Global North, in particular in a city with such a strong colonial legacy as Donchester? My research (which, admittedly, was focussed more on daily experiences than on overarching theories of disability) did not yield significant data in this regard. While international exchange may allow activists to shame the leaders of their countries by exposing the lack of progress made in favour of people with disabilities in comparison to other countries (Heyer 2015), my participants did not seem to engage in transnational activism. In the case of my less tech-savvy participants, for instance the factory workers, this may be due to lack of access to platforms enabling international contacts, or even to low levels of literacy. However, the higher level of education and the familiarity with technology that a good proportion of my other participants had suggests that even visually impaired people

in a position of 'technological comfort', 'digital power' and 'language privilege' (Berghs et al. 2020:4) did not try to leverage it to synergise the progress made in legislation and policy in different countries. There is an international organisation of blind people, the World Blind Union, and yet I do not remember my participants mentioning it. This is even more surprising considering the cosmopolitan nature of Donchester, which is home to people born in different parts of the world. Besides, there did not seem to be an interest in visual impairment as a UK-wide issue, whereas elsewhere disability rights have been linked to citizenship claims at a national level (Sepulchre 2018).

It is also interesting to notice that, even in an ex-colonial power like Britain, the intersection of ableism and colonialism has not attracted much scholarly or public attention. Two exceptions relevant to this thesis, as they specifically look at the challenges faced by disabled people in the domain of employment, are Berghs & Dyson's paper, which looks at black disabled people (2020), and Kim, Skinner & Parish's article, which focusses on disabled women (2020). This is therefore an area for future research. Moreover, the social model of disability that my participants subscribed to did not seem to be informed by the current debates that call for an update of this model. For example, some suggest taking into account the importance of defending the human rights of people with disabilities, which are being eroded (Berghs et al. 2019).

The fissure between the global disability rights movement and visually impaired people in Donchester appears even more worthy of attention in light of the Covid-19 pandemic. The present crisis has brought to the doorstep of people in the Global North problems of a nature and magnitude previously known only to people in the Global South (see Brown & Marí Sáez 2021 on the effects of social distancing on Ebola patients and their carers). For instance, the difficulties in accessing both formal and informal support and in navigating space experienced by visually impaired people in Puerto Rico after the 2017 hurricanes (McCormack 2021) can be compared to the difficulties that people with disabilities had in Britain during the Covid-19 pandemic. For instance, their access to health and social care, and even food, was compromised (Sayce 2021). In spite of the fact that visually impaired people, in particular blind people, can be at a safe distance from others only if others

take the initiative to stay physically away from them, people with sight loss had to fight for grocery retailers to include them into the categories of people who had preferential delivery time slots for online shopping. In Donchester specifically, the assistance offered by the local public transport network, previously praised by visually impaired people, became irregular and unreliable, or even non-existent.

The scholarly literature has already identified areas for improvement. Dickinson, Carey & Kavanagh argue that the pandemic highlighted the flaws of personalised care for people with disabilities (2020), while Pineda & Corburn reflect on the opportunities that the pandemic may provide to implement universal design solutions and inclusive community planning that benefit people with disabilities (2020). The lessons learnt during the pandemic will hopefully provide opportunities for applied research that benefits people with disability both in times of crisis and under normal circumstances.

It should also be considered that, at present, many more people than usual are affected by social isolation because of the restrictions imposed in order to curb the pandemic in numerous countries across the globe. This may exacerbate the chasm that normally exists due to social barriers between those with and without sight loss, a chasm which may prevent the stories of my participants from enacting transformation in others. Visually impaired people are particularly affected by the measures put in place to control the spread of the virus, in particular the misnomered 'social distancing.' They rely on touch more than sighted individuals, and they often need to approach and stay close to sighted people to obtain assistance and to be guided. All the classes at Sunshine have been put on hold and many of my participants have had to give up the outings and social activities that they treasure. Even under normal circumstances, visual impairment often isolates in the professional and in many other domains (creating the 'visually impaired bubble' my participant in chapter 2 referred to), and isolation threatens to beget ignorance of people's respective life experiences. The interactions that my participants, in different capacities, normally take part in and initiate are the first steps towards an understanding that is social, and not just intellectual (Jackson 2005:31). In order to arise empathy rather than sympathy, my informants aim to make others understand them 'as oneself in other circumstances' (ibid:153). In other words, they aim to help

their interlocutors find something in their own experience that is similar to the experience (ibid:31) they have shared with them through communicating to them the outcome of their therapeutic emplotment. Such communication does not happen easily when the separation between people with and without sight loss is too marked, which is unfortunately the case for the more isolated visually impaired individuals. In this regard, we can say that the lockdown has imposed on all of us the isolation that people with disabilities are, sadly, more likely to experience. One of the tragedies of the pandemic was that it made us realise that, for some disadvantaged social actors, the current barriers to interpersonal relationships do not feel new at all.

Adopting 'human sociality' as a method (ibid:32) helps to problematise the relationship between sightedness and sightlessness, which I have maintained in the discussion for illustrative purposes. 'I don't like the concept of disability, because I just see it as everybody has got barriers they need to overcome, or challenges they need to overcome,' told me the ex-CEO of Spring. Like him, I believe any dichotomy (disabled/able-bodied, sighted/visually impaired) is simplistic because each of my participants had a bundle of attributes (personality, interests, skills, etc.) that transcended their level of sight. What is more, even within the remits of the divide between those who do and those who do not have sensory impairments, the picture is complicated. Some visually impaired people themselves admit being ignorant of the challenges faced by people with other disabilities, and are acutely conscious of the significance of filling this knowledge gap by frequenting people with different needs. Interestingly, it should not be assumed that the trauma that triggers the therapeutic emplotment I have been describing is always loss of sight: it can also be acquisition of sight. Oliver Sacks (1993) and Richard Gregory (1998) each described the struggle of a man who had been blind from birth and suddenly had to adapt to life as sighted following medical intervention. Gregory called his case study, as well as similar ones, 'interesting and dramatic' (ibid:158), while Sacks concluded that 'learning to see demands a radical change in neurological functioning and, with it, a radical change in psychological functioning, in self, in identity' (1993). In other words, sight acquisition did not restore the person to a 'default,' positive situation. On the contrary, like sight loss, it entailed a deep reframing of one's sense of self. It is not surprising that, for my participants, gaining or regaining their sight, i.e. a restitution narrative (Frank 1995:75-96), was hardly ever a desired prospect.

The way in which the intellectual study of sensory impairment can be used to overcome the duality between the sighted and the sightless, as well as many others, is cogently articulated in the correspondence between two philosophers: Magee, sighted, and Milligan, blind from shortly after birth (Magee 1995). The book conveys a positive message: Magee argues that, although, unlike some other animals, we as humans cannot perceive infrared light, we do not consider ourselves impaired (ibid:15-16). He elegantly concludes that 'the difference between what the blind miss and what the sighted miss must be as almost nothing compared with what we all miss' (ibid:28). Put differently, what we think of as fully equipped human beings are individuals who share the same sensory limitations as us. A reconciling message emanates from the book: 'what matters […] 'on the human scale' is not the 'vastness' of difference between human beings [e.g. sighted and blind], […] but the extent to which we can unite in a community within which we can gain from and be strengthened by the differences between us' (ibid:53). This has deeper implications: 'If people could believe that each of us lacks something that only an other can fill […], then empathy would no longer be spoken of as something one person "has for" another. Instead, empathy is what a person "is with" another' (Frank 1995:150).

My participants brought to my attention the fact that 'we can all become disabled at the drop of a hat,' that disability 'is a category anyone might enter through aging or in a heartbeat' (Ginsburg & Rapp 2013:55, cfr Levy & Storeng 2007:61). When talking of 'common humanity,' following Magee I refer to much more than the connection that the able-bodied may feel to the disabled when they fear they might lose their physical or mental capacities. The common humanity I want to bring to the fore is one that blossoms when self and non-self meet and give rise to 'something new that is greater than its parts' (Napier 2003:197). It is one that acknowledges that 'other' is not a 'non-self,' but a different self, in which we can see ourselves (ibid). In fact, 'diversity, difference, and otherness are not the opposite of mutuality, but the conditions that bring it into being as people attempt to understand one another through ongoing dialogue and interaction' (Irving 2009:294-295). This common humanity, or 'mutuality,' is one that does not hypocritically preach diversity without giving everyone equal chances (see Stiker 1999[1982]:150, see also ibid:137), nor one that repackages stigma as economic value without considering the

consequences this may have on those who bear that stigma (Friedner 2013, Friedner 2014, Friedner 2015, Friedner & Osborne 2015).

It is this type of mutuality, or common humanity, that is at the basis of the exemplary and co-constructed nature of therapeutic emplotment, and that makes the therapeutic emplotment achieved by visually impaired people beneficial to them, their interlocutors and society at large. To summarise, it benefits first of all people with sight loss. I think it is appropriate to lay emphasis on the communicative side of the experience, as 'the telling is as much a redemptive act as are the acts that are told, for telling the story sets an example and provides an impetus for change' (McAdams 2006). In a similar vein, it can be argued that 'when, in a relationship we are positioned in a manner which permits the conscious elaboration and *communication* of loss we become more real and internally whole' (Watermeyer 2009:98, my emphasis). In other words, by noticing how their stories affect and even empower others, disabled people may feel encouraged to adhere to their newly found equilibrium in spite of all challenges.

Secondly, common humanity benefits those who frequent people with sight loss. In fact, they may feel spurred to overcome their own challenges by taking the therapeutically emplotted lives of visually impaired people as a model, in the Richard Sennett meaning of the term. People with sight loss may frequent people who are visually impaired themselves. In this case, they may feel the need to give back to the VI community discussed in chapter 2 (cfr Henry 1995:288-289). Those who frequent people with sight loss may also be sighted. The focus of my research were blind and partially sighted people themselves, but during my fieldwork I inevitably came into contact with their family members and friends, as well as with the volunteers who provided assistance and with simple passers-by who had short interactions with them. I do not wish to dismiss the difficulties that visually impaired people may encounter even in social circles they are part of, such as their work environment or family. However, my impression was that the closer an individual was to the visually impaired person, the more the former felt empathy rather than sympathy towards the latter. In other words, they interacted with them without holding what separated them, their level of sight, 'their strangeness,' 'against them' (Bauman 2000:104). As

Goffman pointed out, it is much easier to stigmatise (i.e. to make a stigma, a flaw, stand for the whole person) a stranger than a known person (1990[1963]:68-70).

Society at large may also benefit from a therapeutic emplotment shared in a context where common humanity is the glue. In the encounter between my participants and the recipients of their stories, be these stories the tales of a storyteller or simple lived experiences, the latter may become aware of the change (of career, outlook on life, etc.) that people with sight loss experienced, a change that is the crux of therapeutic emplotment, as it is pivotal to all narratives. Insofar as 'we become particularly interested in the things we can change' (Sennett 2009[2008]:120), visually impaired people's interlocutors may feel compelled to harness the common humanity between them and other people in order to help bring about change in others — all kinds of others — in a broader social sphere. In her account of her sight loss, Unni Wikan points out that it took her own illness for her to vividly become aware of the world of the ill, which she merely knew intellectually: 'cultural knowledge is accumulated only as it becomes relevant to one's life,' she states (2000:223). It is not difficult to see that this assertion could be countered by an attitude towards others — not only significant others, but all others — that is more open, empathetic and curious. We are socialised not to stare, but this, rather than fostering politeness, seems to be suppressing the construction of a common humanity. It is perhaps no coincidence that many activists and disabled people have addressed the visibility of the latter (see Fudge Schormans 2014, Mji et al. 2014, Rice et al. 2015, Sandell, Dodd & Garland-Thomson 2010), as well as the visibility of people who are ill (see Guevara & Nouvet 2011). I would argue that by cultivating an interest for our common humanity we could obtain a knowledge of the other that is not just a product of theory, but a consequence of our relationships (Jackson 1989:34). Such knowledge is an essential basis for the diffusion of the therapeutic emplotment attained by my participants beyond the self, and beyond the dyadic relationship between a visually impaired person and her interlocutor.

Blind writer and academic Georgina Kleege discusses the use of Braille in public spaces in the United States following the passage of the Americans with Disabilities Act (ADA) in 1990 (2006a). She notices how the use of Braille is sometimes a mere display of compliance with the law (ibid:211), a decorative motif (ibid:213) or, even

worse, a metaphor for ignorance (ibid:214-215). She argues that, if Braille were used with the genuine intent of being read by the blind, inclusiveness would be truly fulfilled. Along similar lines, with this thesis I advocate the practice of a type of anthropology that, like the contribution of my participants, is not overtly militant, but is not 'decorative' (Kasnitz & Shuttleworth 2001:8) either. I also advocate the practice of an anthropology that, rather than speaking 'from paper' (Cruikshank 1998:45), proves 'its utility for the people it studies' (Kasnitz & Shuttleworth 2001:8) but also, more importantly, for the people among whom they live. In so doing, I propose an academic practice whose benefits are spread beyond the restricted circles of research participants. Clinicians and medical practitioners, for instance, are an important category of people who interact with visually impaired individuals whose practice could be informed by the present work.[46] A contradiction has been noticed between the ubiquity of stories in clinical practice on the one hand and medicine's wilful neglect of the narrative dimension of illness on the other (Good & DelVecchio Good 2000). In highlighting to medical professionals the illness facet of the ophthalmological diseases they treat, this thesis posits 'moral experience' as 'a key to understanding persons and their worlds' (Kleinman 2006:196). In other words, in order not only to cure a disease, but also to heal an illness, it is important to know 'what really matters' (Kleinman 2006) for the patient. The present work has attempted to shed some light on the things that are at stake for my participants.

There is a tendency to give prominence to the tragedy of disability and to its deleterious effects on employability. This thesis encourages the reader to look beyond the negative effects of disease and its social consequences on work chances. It aspires to follow Joan Ablon's advice to use disability as a prism for social understanding (1981:7-8). It also responds to Mary-Jo DelVecchio Good's incitation to study further developments of the relationship between pain and the therapeutic power of work (1992:70-71) by suggesting that it is appropriate to include in this analysis other types of 'work' besides the professional one, because work is imbricated in different life domains. In my approach, I espouse Baer et al.'s appeal to re-label medical anthropology as 'health anthropology' (2016). They argue that this

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[46] Cfr Shuttleworth & Kasnitz 2004:145 on the similar aims that Joan Ablon had in her pioneering anthropological research with people with disabilities.

term describes more realistically the plethora of realities, besides allopathic medicine and ethnomedicine, that are explored by scholars in this branch of the discipline (ibid:495). They also contend that their chosen definition of medical anthropology is better than the traditional one in rendering the social, rather than individualistic, nature of wellbeing (ibid:496). Through the present work, I have attempted to shed light on both issues: the multifarious factors that contribute to the wellbeing of my participants, and the social situatedness of their illness narratives.

The 'portraits' I have written are testimony to the 'slow, contemplative moment with another human being' (Bray 2015:121) that is one of the greatest rewards for both a portrait painter and an ethnographer. The 'portraits' I presented are drawn on these pages as crystallised life stories, fixed like an inspirational portrait hanging on the wall. Perhaps they will be revisited by their 'sitters' who, re-reading their own stories, may be reminded of their hard-fought achievements and of the better self they have become. The subject matter of the portraits is in fact the particular self that has been emplotted therapeutically. As such, these portraits may act as a further anchor to the rocky boat that is therapeutic emplotment, while leaving their 'sitters,' my participants, scope for further transformation. A personal story is ultimately open-ended, as it 'allows us to see that — from other perspectives and/or through alternative 'editing' — other stories might have been told' (Garro & Mattingly 2000:18). After all, if sitters can be regarded as characters and not narrators (Mattingly 2000:185), they know how things began, but not how they will end (ibid:184, Wikan 2000:215). They enjoy a liberty that is both enticing and daunting.

Moreover, as the joint effort of me, the researcher, and my interlocutors, the portraits' power to bring about change is not a solipsistic enterprise. As I have argued, therapeutic emplotment is more solid when it is co-constructed. Because of the dynamics of therapeutic emplotment, which can spread through society at large, the portraits that constellate the thesis may also leave these pages to reach a broader readership. Stories circulate, and then 'what is needed by the heart will settle in the mind' (Narayan 1989:47): when they cross paths with those who need them, they start producing their effects. Indeed that is their main purpose, to 'kindle in [many] soul[s] a noble longing' not so much 'for glory and honour,' but for pursuing 'the ultimate freedom,' that 'to decide […] what is it that makes life worth living' (Graeber

2001:88). With this thesis I have, generally speaking, adopted the point of view of my participants: I have adhered to the messages they wished to convey through their life narratives and espoused their worldview. This has been a conscious decision: by giving space to their voices I have intended to create a counterbalance to a social context where people with disability often suffer from coerced passivity, if not infantilization.

It must not have gone unnoticed that my thesis is dotted with visual references, which is quite at odds with the topic of discussion. I opened the first chapter by saying how intrigued I felt when I realised that there were visually impaired people going to art galleries to take part in audio-described tours. A visually impaired person in a gallery? An oxymoron, at first sight, 'matter out of place' (Douglas 2002[1966]:44). Visual references in a thesis on visual impairment? Equally 'dirt' (ibid.). At a closer look, both are ways of challenging the divides that are so engrained in our society that they are overlooked, passively accepted. The aim of this thesis has been to contribute to a more enlightened view of human diversity.

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