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**Exploring accountability, human rights and legitimacy from a
disability equality perspective**

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Abstract:

Matters of sustainability rarely deal with issues of disability from an equitable perspective – that is, putting disabled people’s voices within a wider conversation that informs mainstream debate. As a group, the disabled population are ignored; a silencing imposed on them as untrustworthy speakers, and thereby denied a role as authors of knowledge marginalises them. This has a trickle-up effect with regard to worldwide affairs, the complexity and nuance of debates nationally, the presentation of theory within disciplines and ultimately the rejection of disabled people’s individuality and humanity. While this silencing is critical to the methodological, ontological and epistemological concerns of many subjects, lack of recognised authority has led to a denial in participation more widely characterised by an issue of trust in society. This research is based on an ethnographic observation provided an exploration of accountability, human rights, and legitimacy with a disability sensitivity. The research used language policy as tool of analysis to explore the way globally narratives erode what should be for disabled people an unalienable entitlement to human rights. Through a 5-point scale, a web of accountabilities, helps articulate how a dialogue may help counter ableism in a spirit of co-production. The vignettes from the empiric site give a representation of accountability in conversation and activity. The reflection and theorisation then informs a specifically activist interpretation of legitimacy theory, one that could keep the interests of the disabled population at its heart. Overall, the text stands as a rough example of theoretical blending that seeks to avoid domestication of disabled people’s voices that could inform that of other work, within organisations seeking to secure greater commitment to human rights through addressing inequality within their culture.

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List of abbreviations:

ASE	Accounting for Society and the Environment
IL	Independent Living
ILF	Independent Living Fund
IMF	International Monetary Fund
IR	Integrated Reporting
OECD	Organisation for Economic Co-operation and Development
PCP	Person Centred Planning
SDG	Sustainable Development Goals
SDS	Self Directed Support

Glossary of terms

Ableism: a specific type of oppression, akin to homophobia, racism and sexism, held in the culture and language that inform society's debates.

Anti-ableist: a defined position against ableism, an oppression that disabled people face specifically – like feminist or anti-racist.

Citizen: defines a person acting in a community space, such as in a political role as activist or protester. It defines an individual being publicly and politically, speaking beyond personal boundaries, and often within state or government boundaries.

Buyer, client or service recipient as an individual acting within a paid exchange – knowingly or not.

Community member: used interchangeably with citizen and neighbour, to indicate a person speaking in a non-paid or non-political role.

Craftivism: activity chosen as both craft and activist, characteristically small, unique and challenging a wider narrative.

Crip theory: theories built on the academic knowledge base of disability studies

Disablism: a specific type of oppression levelled directly at disabled people, much like misogyny or religious hate speech, that operates in community of practice within and across organisational boundaries.

Orthotoxic: portmanteau created for the thesis blends orthodox, meaning traditional and conformist, and toxic, meaning poisonous and noxious. Orthotoxic describes the characteristics of language and culture that characterise ableism and thus cause harm to disabled people.

Queer theory: theories built on the academic knowledge of sexuality studies, explaining the articulation of anti-homophobia; often linked to crip theory in literature.

Worker defines a person in a paid role, e.g support worker, an individual who performs activity in exchange for payment. Defines a person in a paid role. Not in a citizen or consumer role but in a job. The word 'professional' has been used occasionally where authors are cited; and in one heading where a P was needed.

Worker, citizen and consumer are not used interchangeably but define the role of a person in different conversations in relationships and circumstances. The words are defined thus to tease out the relationships between the workers and clients. The distinction helps to highlight societal narratives, within an overly consumerist where a market conversations often replaces the other two. These are arbitrary distinctions for the purpose of the document.

In the following passage Jean is a composite. The prelude, and following interludes, provide a less academic way of telling the human story that sits beyond the research text. The words are in italics to represent speech. In a non-academic way the individual voice in these sections speaks for thousands of people living in institutions in the United Kingdom.

Prelude – on the edge of the edge

Jean sits on the edge of the edge... not simply that of the bed.

Her limbs ache and her thoughts are fuzzy. The medication will take half an hour to kick in, which will take away the physical pain – partially. Unfortunately, leaving her with other problems such as memory loss, anxiety, and nausea. In the ‘care home’ the wake-up call had been disconcertingly early, there was no privacy, and washing and dressing had been a ritual shame. Often people were stripped and sprayed with cold water. She had no name, no key, no smokes, no freedom... Jean had no control, and nobody knew her pain.

Jean’s day stretches ahead dauntingly: negative comments, harassment, applications, rejections, and refusals ... more shame. Jean feels that while she is praised for getting out of bed, but she is then pilloried for asking for help to do so. She feels vilified for not having a job, confused each time she is expected to work for nothing, and mortified by the daily rejection of asking. In a world where everything costs, she has very little money, and no hope of more - insecurity is overbearing and ever present.

When she does get out the probability of scorn is high, insults are a daily occurrence and verbal attacks are frequent. Access to buildings is problematic, attitudes are often negative, processes are daunting and intelligible - generally she feels unwelcome in public. A reaction to stress, her coping strategies, drink, drugs and self-harm, all decrease the likelihood of happiness and wellbeing; and increase the likelihood of prolonged inactivity, poor emotional strength and declining physical ability. Similarly to many, when Jean talks about belonging, it is with uncertainty, longing and sadness. When she talks about acceptance it is with the pain of rejection, with shame and self-loathing. Dignity, choice and optimism are ephemeral, often disapproved of by others, and unreasonably conditional.

Should she happen to cave under the weight of pain, the pressure and isolation brought on by shame, the stress is likely to cause illness. At the end of the day Jean sits on the bed. Teetering on the point of no return, she counts out the pills and plans the end... She’s on the edge of the edge of the edge.

Part one

Chapter One: All Voices Count

1.1 Voices in the world

“**Where are the voices of disabled people?**” is the question that brought me to this work, an interest that was born out of a hunch. Having worked in a lot of organisations, many having disabled people as clients and workers, I had noticed that their voices – or more widely that of the disabled people’s movement – went unqualified. As a feminist - an activism with a name - for many decades, it puzzled me that there was no similar language for articulating the interests of the disabled population. Also, given the articulation of disabled people as a named group in law, a group with ‘protected characteristics’ under the Equality Act (Equality and Human Rights Commission, 2018), I often asked myself why the interests of the disabled population were ignored (Lightbody, 2017). In Scotland, where human rights seem to be very much on the agenda, the vocabulary used to talk about disability is blunt, clunky and confusing. This lack of fluency could possibly be due to a form of testimonial injustice with distinctive characteristics (Fricker, 2007). As storytellers, voices within the disabled population - the anti-ableists, like feminists, abolitionists, civil rights and anti apartheid protesters before them - add divergent ideas to debates about inequality in view of their group’s disadvantage. These ideas provide a discourse that stands in opposition to the assumptions that are underpinned by stereotypes and characterise disability and its form of specific prejudice. As evidence has shown in other disciplines, it is our belief, and not our thinking, that can lead to unconscious bias (Fine, 2010; Beresford, 2016).

The thesis argues that the development of more nuanced language to further the rights of disabled people, which includes the introduction of an anti-ableist sensitivity, would help tackle the silence surrounding disadvantage, injustice and harm. The investigation was undertaken in the spirit of the accounting for society and the environment movement, and a call for researchers to ‘investigate the flow of resources from organisational constituencies as well as the pattern and content of communications’ (Hybels, 1995, p. 244). The human rights of the disabled population should

concern us all, as most of us are touched by disability in some way - if not personally impaired then by others within our relationships. In the global-north the likelihood is that most of us face the reality of old age and impairment (Priestly, 2003). It seems strange, therefore, that sustainability is rarely critiqued from a disability perspective in a nuanced or an articulated way, particularly given that disabled people are now highlighted as one group of specific interest within policy. Yet, despite being a protected characteristic under the law, strategic decisions still largely affect disabled people disproportionately unfairly (Fenney Salked, 2016). As the National Director of the Equality and Human Rights Commission states, disabled people face a social apartheid: “Far from enjoying increased visibility and being able to participate more fully in every aspect of life, there is a risk that disabled people will become more invisible as both consumers and participants... positive changes are masking increased social isolation for many disabled and older people as Britain’s society and economic life undergoes significant structural changes” (Naysmith, 2015).

The intervention is set in an organisation where clients are disabled people, a space where relationships with them are more ordinary than they are elsewhere. Extended visits provided the basis for a textual account, a story told in 5 vignettes, where the mundane becomes representative of what is atypical elsewhere. While the focus is on accountability, the analysis frames legitimacy as a dialogue that extends participation along 5 axes (web of accountabilities). By inviting divergent voices into conversation and acknowledging specific authors in storytelling / reporting, accountability is extended and secured to human rights agenda. The analysis finds ‘talking up’ hospitality, citizenship, control, anticipation an ‘investment’ in community, capacity, individuality and hope. Where ableism is defined as the character of a distinctive oppression, like racism or sexism, imposed on the disabled population. Theorising anti-ableist legitimacy as an explicit/implicit contract, narratives can explored to help articulate a legitimacy that holds disabled

people's empowerment at its heart. The text stands as an example of theoretical blending, which seeks to redress the avoidance and domestication of disability studies in other academic work.

Overall, as the aims explain in section 1.4, the research sought to highlight an absence of voice in the textual presentation of disability, to explain a lack of terminology in human rights discourse, to suggest an accountabilities framework, illustrate this empirically and finally, to explore learning from word and experience, offering a challenge to legitimacy from a disability perspective. Finally, trust emerged as the touchstone, the thread, the tie, the overarching glue pulling this text together. As Hawley suggests, trust is 'at the centre of a whole web of concepts: reliability, predictability, expectation, cooperation, goodwill, and – on the dark side – distrust, insincerity, conspiracy, betrayal, and incompetence' (2012, p. 6).

1.2 Sustainable Development



Fig 1.1: The marble

The image of the earth as a marble was a defining point in history, and for many it was the first presentation of the globe as a single entity. To this day it serves as a representation of the connection between planet and people - the environment and society. It is a place where Jean should

feel she belongs, part of its story, part of its action. She ought to be one of its many storytellers, one of those who holds its past, creates its present and shapes its future. But for many she does not exist, her experience is not counted, she falls outside the ‘norm’, the typical Joe on an ordinary bus. In education her learning is not viewed as progress, in work her contribution does not count as paid, in housing her needs do not count as priorities, as an academic texts her knowledge is bent and moulded to count as someone else’s data, as a citizen she is not counted as a neighbour, mother, daughter, wife or friend. While some plop their empties in the correct bin and call it being ‘green’, for many such a luxury is meaningless in the small matter of surviving the harm in a fight to stay alive in a world littered with words that are toxic. As the *Adapt Now: A Global Call for Leadership on Climate Resilience* report states:

Climate change exacerbates existing inequities by widening the gap between people with wealth and people living in poverty. (World Resource Institute, 2019, p. 2)

Until recent months, stories about our planet have talked of sustainability as an interest that is somewhat separate to the globe as an indivisible whole. Rarely viewed as an imperative, discussions about human rights were not placed at the heart of those about sustainable development. For many the impact of growth was ignored in the face of its measure as proof of development of nations. Thus, overshadowed by a denial of its implications for life on the planet, an ambivalence could be observed. To paraphrase Hawken (2007), it was a choice, to get on board the environmental or on the social justice bus, while ignoring the impact of the later on the former. He argued that the wrong questions were being asked as both run out of road. Yet growing evidence suggest negative impact of inequality is currently threatening the lives of people like Jean, as the levels of unsustainable, unchecked and uneven growth impose hardship and destruction (Wilkinson & Pickett, 2009; Marmot & Bell, 2012; Bebbington & Unerman, 2018). Furthermore, issues of social justice are often seen as either /or propositions, broadly: to save the whales or to feed the starving. It is only recently that the literature has grown proposing an and/and/and view of such

matters, linking issues, interests and crises as a deeply woven into an uneven global fabric. It is more recently that issues of social justice have come to be seen as deeply enmeshed in sustainable development. Therefore, there has been a lag in the language, with new vocabularies emerging to define ideas relating to this complex emerging view. With regard to politics, populations, groups and their activities are often still spoken of in simplistic terms; setting up binary continuums resulting in confused conversations where similar words poorly define much more nuanced ideas. The narratives used to define modern day lifestyles, the power held in the texts that hold ideas (Thompson, 2007), add to the oppressive nature of growing inequalities within social arrangements that fuel hardship and poverty for many, and injustice for all (Pickett & Wilkinson, 2017).

The Sustainable Development Goals are 17 priority areas that were set by the United Nations General Assembly in 2015 for the year 2030 to address worldwide problems. Since its introduction through the UN's Brundtland Commission (Our Common Futures, 1987), accounting literature has changed the language of sustainable development, defining it as 'being a guiding principle bridging environmental and human development concerns' (Bebbington & Unerman, 2018, p. 2); and during 'the last decade, a new body of research, led by the Organisation for Economic Co-operation and Development (OECD) and the International Monetary Fund (IMF), has found that economies with more equal distributions of income and wealth tend to have stronger and more stable paths of economic growth than those with greater inequality' (Berg Andrew, Ostry, Tsangarides, & Yakhshilikov, 2018). This goes some way to help identify the language of equality and definitions of human rights and equity as critically important to an understanding of sustainable social and environmental accounting (Li & McKernan, 2016), and supports a growing fluency around respect and accountability more widely among working networks (McPhail & Adams, 2016). For what follows, the lens of the Sustainable Development Goals has anchored a certain perspective, with 16 being a central touchstone: 'Peace, justice and strong institutions - Promote peaceful and inclusive

societies for sustainable development, provide access to justice for all and build effective, accountable, inclusive institutions at all levels' (Bebbington & Unerman, 2018, p. 6). To achieve sustainability, for those of many generations to flourish, inequality needs addressing so that lifestyles begin to help protect the planet, respect life on it and remedy the existing causes of harm (Ruggie, 2008). Across more generalist literature, while many agree that sustainability is a 'good thing', definitions are often tailored to specific interests and geared towards chosen agendas, this inner view of one organisation, institution, or industry avoids the more complex and overarching aspects of both globally and locally entrained issues which may sometimes appear to compete (Braungart & McDonough, 2009; Goodhall, 2012; Atkinson, 2014; McDonough, 2013; Caradonna, 2016; Robertson, 2014). The social aspects of Ruggie's guiding principles that help question politics and citizenship suggest that human rights need to have a central position in business, because in corporate accounting for example, accountability practices could provide the 'due diligence practices and [the] corporate-based non-judicial access to remedies for those whose rights have been violated' (McPhail & Adams, 2016, p.651). The political impact of ideas links to accounting research as 'inevitably political in effect, even when undertaken by self-conscious researchers who adopt a policy of detachment and restraint - rather than interventionism and reformism' (Lehman & Tinker, 1987, p. 519). It seems fair to ask what kind of economic system would lead to everyone's needs being met in an ecologically sustainable and socially just manner? (Bebbington, 2011).

With regard to the disabled population, the United Nation's call within the Sustainable Development Goals to address poverty and reduce inequality is pertinent to a group found within all communities. Because, disabled people often struggle to get the support they need to have their human rights respected (Berghs, Atkin, Graham, Hatton, & Thomas, 2017). While sustainability debates speak of the wellbeing of future generations as 'our neighbours in time' (Robertson, 2014,

p. 6), it seems ironic that today, now, many of our neighbours are suffering due to ill-conceived policies within systems that deepen poverty (Wilkinson, 2005; Glasser, 2020). In the interest of justice, viewed as less unsustainable development, distortion in mainstream storytelling is exposed as insufficient and ‘efforts to tackle inequality might harness the power of ideas: tackling ‘norm perceptions’ (beliefs about what others think and do), publicising positive deviance and strengthening social movements’ (Evans, 2018, p. 360). This document, on the other hand, is an attempt to speak about systemic inhumanity, by highlighting a number of realities imposed on disabled people’s lives. In order to *prove* that it is an alternative way to enhance the lives of individuals, in ways that also address the interests of those in the civil rights movement who are voicing the injustice they face (Klein, 2014).

For workers, and the disciplines that guide them, sustainability debates need to include an obligation to society. The zones of tension created by ideas, those held by organisations on the other hand and their stakeholders on the other, often challenge more widely held assumptions about the good for society, the interests of civil groups, and global priorities more widely (Tilt, 2003; Deegan & Unerman, 2011; Gallhofer, Haslam, & van der Walt, 2011; Thomson, 2014). Evidence suggests that growth linked to privilege affects the increasing inequality that has led to numbers of people suffering hardship, because left unchecked unsustainable growth threatens both environment and society, and material-intensive production and exploitative social relations are both unsustainable (Bebbington, Unerman, & O’Dwyer, 2007; Bebbington, 2011). High status, advantage and privilege affect relationships between groups in society and acknowledgement of this marginalisation has led to interest in their relationships to global issues in social and environmental accounting (Berghs, Atkin, Graham, Hatton, & Thomas, 2017).

1.3 The disabled population

The literature analysis shows a noticeable gap where it comes to the expected contribution from disabled people as a civic group. In chapter four, debates about human are looked at to show the ways in which shared stories fail to speak for all, and the characteristic marginalisation of disabled people's voices in a globe/local conversation. Texts are explored to identify misrepresentation in language and culture, to help define accountabilities that reflect an understanding of anti-ableism. Where ableism is defined as the character of a distinctive oppression, like racism or sexism, imposed on the disabled population. The thesis will draw on sustainability, accountability and human rights literature, highlighted as critical in the observation of empiric culture through an ethnographic lens, to produce a text that articulates the emancipation of disabled people.

A legitimacy gap, characterised by silencing and articulated by the misrepresentation of the interests of disabled population, means that while disabled people's rights are often violated, as a sizeable group their specific interests are largely ignored. Outside the field of disability studies, few know fully of the extent to which the lives disabled people are subject to hate, pain, and disadvantage, and even fewer have a language to speak of this injustice with nuance (Beatty & Fothergill, 2013). Despite legislation, often an overbearing defence of an organisation's discrimination establishes lack of blame rather than positive progress. This in terms of sustainability raises questions for human rights. These have moved from obscurity to urgency on an agenda of global proportion over the six-year span of the research. In global debates where every citizen needs a voice, those with more power and influence often lead the conversation. Despite the high profile and all-encompassing nature of the Sustainable Development Goals, scale and complexity often leads to the disempowerment of those most marginalised by distorted debates. The silencing of those most harmed by society's inequality is hidden in a world where advantage offers volume to those already visible. Organisational legitimacy may be thought of as a commitment to establish

congruence between its purpose and values held more widely in society. However, a threat will exist to organisational legitimacy where ‘the norms of acceptable behaviour in the larger social system... [where] an actual or potential disparity exists between the two value systems’ (Tilling, 2004, p. 4).

As the United Nations states: ‘There is growing consensus that economic growth is not sufficient to reduce poverty if it is not inclusive and if it does not involve the three dimensions of sustainable development – economic, social and environmental... To reduce inequality, policies should be universal in principle, paying attention to the needs of disadvantaged and marginalized populations’ (United Nations). It says much about disabled people’s marginalisation that none of the Sustainable Development Goals specifically outline the outcomes of the inequality disabled people face. However, as chapters 2 and 4 explore in detail, this is a neglect of attention given to disabled people as a recognised group appears in many areas of literature, including those relating here to accountability, human rights, and legitimacy (Woodhams & Danieli, 2000; Saffer, 2017). Hidden, forgotten or silenced, the absence of disability on the academic roll call outside disability studies is an identified trend in research (Woodhams & Danieli, 2000). Accountability can only be achieved if the interests of the disabled population are explicitly stated central to purpose, requiring a dialogue to secure knowledge by all parties. From an equality perspective, inequality is recognised as sitting above the harm caused directly to individuals from marginalised groups (Li & McKernan, 2016). So far, emancipation has not altered an articulation of the societal issues at the core of sustainability in order to be acknowledged more widely by the accounting profession (Gallhofer & Haslam, 2006).

1.4 Aims

The aims below seek to answer a plea for a more nuanced analysis and theoretical exploration of what it means to support sustainable development in real settings (Gallhofer & Haslam, 2011; Gray, Adams, & Owen, 2014).

Research aims:

1. Provide an ontological, epistemological and methodological description of the silencing of disabled people's voices.
2. Outline evidence-based knowledge in order to characterise the distortion of ableism in storytelling in order to apply an adjustment to it in the analysis, observation, reflection and theorising.
3. Outline methods that are suited to the site and its culture that also respond to specific ethical constraints.
4. Provide a textual analysis that illustrates the voids and distortions in human rights narratives.
5. Propose an idealised framework for accountability, a conceptualisation through which a human rights imperative can be extended and maintained as conversations to secure legitimacy with the disabled population.
6. Provide a text, based on an empirical observation of culture, language and practice.
7. Provide a reflection on the text, identifying themes that relate to human rights, presenting society needs to address inequality, discrimination and prejudice as investment.
8. Propose a theorising that adopts a radical intent that crosses boundaries to secure anti-ableism in other fields.

Overall, the research found that the lack of trust held in the voice of disabled people in mainstream debates ultimately tends to negate their participation. The intervention is set in an organisation

where disabled people are the sole clients, a space where relationships with them are more ordinary than they are elsewhere. Extended visits provided the basis for a textual performance, five vignettes where the mundane becomes representative of what is atypical. While the focus is on accountabilities, the analysis frames legitimacy as dialogue that extends participation along five axes. By inviting divergent voices into conversation and acknowledging specific authors in storytelling/reporting, accountability is extended and secured. The analysis finds ‘talking up’ hospitality, citizenship, control, anticipation an ‘investment’ in community, capacity, individuality and hope. theorising anti-ableist legitimacy in an explicit/implicit contract of hope and trust.

1.5 A marginalised group

The percentage of disabled people varies across the United Kingdom. Scotland’s figure of 22% suggest that far from being a small group living in an alternative world, the disabled population is distributed pretty evenly (Papworth Trust, 2018). These figures also tell us that there are 4.2 million disabled people living in poverty, accounting for 20% of all people living in poverty; and there are more disabled women (23%) than disabled men (13%). Disabled people are twice as likely to be unemployed than non-disabled people, and by the age of 26, disabled people are four times as likely to be out of work or out of education compared to non-disabled people.

Impact

- Disabled people are twice as likely to have unsecured debt totalling more than half of their household income.
- On average, disabled people have £108,000 less in savings and assets than non-disabled people.

Poverty

- There are 4.2 million disabled people living in poverty, (ie 20% of all people living in poverty).
- Of disabled people living in poverty, 2.8 million are working aged adults, 1.1 million are pensioners and 320,000 are children.
- Disability is strongly linked to poverty. 30% of people in families with disabled members live in poverty, compared to 19% of those who do not.

(Papworth Trust, 2018)

Having an impairment or difference does little to explain these startling figures. The factors affecting the group go way beyond individual identity. In the same way gender politics has given a language to the inequality women face, disability politics has led to a growing awareness of the organisation that operates beyond disabled people as a specific group. Disabled people are characterised as a marginalised group given the specific and oppressive discrimination they face, and the unique character of its representation against a privilege afforded by perfection and beauty defines it best as ableism (Goodley, 2014). It is the notion of ‘able’ as norm, not other, that defines the group as disadvantaged by their lack of privilege; by the unearned privilege afforded to those that do not need to question their own humanity repeatedly (Davis, 2013; Pease, 2013). Injustices, as Jean tells us, may be experienced at a personal level but need to be acknowledged at political and theoretical levels to address population interests that are local, national, global and led by practice development and policy decisions (McPhail & Walters, 2009; Bebbington, 2011; Deegan & Unerman, 2011). Most recently, the United Kingdom’s tack record for social justice was highlighted by the United Nations committee for the Rights of People with Disabilities as a ‘human rights catastrophe’, in which the status as world leader was said to have slipped (Equality and Human Rights Commission, 2018). A point restated more recently by Disabled People's Organisation campaigners in July 2018: “Disabled people’s complaint was upheld. The UN disability committee published the findings of an extensive investigation which found evidence of grave and systematic violations of Disabled people’s rights due to welfare reforms” (Aspie, 2018).

Given the character of the impact of inequality on so many, disabled people are recognised as the biggest global *minority* by the World Health Organisation. After all, people rarely escape impairment since ageing is far more likely to lead to impediment than wisdom. Yet, despite this societal perspective, disabled people cannot truly be described as a minority in terms of numbers (Barton, 2005; Barnes, 2010). Papers on sustainability and disability are infrequent, as stated by the

Journal of Interdisciplinary Perspectives on Equality and Diversity: ‘focus on climate change and disability is disturbingly rare... research and advocacy agenda for both the Climate Change and the Disability Rights movements’ (Saxton & Ghenis, 2018, p. 1). As I write, journalists are reporting on the Ryanair story about the abuse directed at a disabled black woman from another passenger (People Management, 2018). Racism is clearly mentioned in the coverage, yet as days have passed mention of disability has fallen from accounts, a clear indication that as an oppression ableism is not recognised, as a word, or as a crime.

In intersectional literature, disability as a category, as identified in legislation since 1999, is frequently omitted, misrepresented or ignored completely (Lightbody, 2017). Given that 15% of the world population are disabled (Scope, 2017), individuals with impairments make up a large proportion of any chosen representative group. While the Sustainable Development Goals *do theoretically* reinforce an entitlement due to their focus on human rights and equalities (Bebbington & Unerman, 2018, p. 11), more broadly, texts should relate to the area of social justice that social accounting aims to contribute to in terms of emancipatory vision (Gallhofer & Haslam, 2011). When considering disabled people, accounting for the inequity of their access to the world’s resources seems critical to most goals, yet to date ‘there is little accounting research that systematically explores links between accounting and economic equity’ (Tweedie & Hazelton, 2015, p. 113); and bearing in mind that ‘research is required to examine how equity considerations might affect decision making in other areas of social good delivery such as health and education’ (Hunt, Staunton, & Dunstan, 2016, p. 1371). This work follows a new trend in research, of exploring culture and language within alternative forms of reporting, as accounts and performance, where texts stand as the speaking and the writing of organisational storytelling (Macintosh, 2002; Kamuf, 2007; Gibbon, 2012; Li & McKernan, 2016; McPhail & Adams, 2016).

1.6 Accountability and civil rights

Flower has stated that ‘an accountant’s duty is to report the truth, not to exploit others’ lack of knowledge and thereby mislead them’ (Brivot & Baud, 2018). This suggests the need for ‘new avenues for investigation and theorization, also prompted by the Sustainable Development Goals due to their acknowledgement that accounting needs to look beyond its discipline to ‘domains of scholarship including natural science, other social sciences and humanities’ (Bebbington & Unerman, 2018, p. 18); hence the use of theory development ‘based on correspondence involves a meaningful engagement with both domains... blending is the operationalization and extension of correspondence insofar as constructs from two domains are merged to produce new insights’ (Oswick, Fleming, & Hanlon, 2011, p. 328).

In the following, the jagged edges of several domains have been engaged with, in an attempt not to domesticate but add to an understanding of accountabilities. A web of accountabilities was used as a representation of these divergent conversations extending a financial dialogue to encompass ideas of political, public, innovative and governance significance (in chapter 5). The web of accountabilities thus created has its application, through language policy and disability equality, to legitimacy theory in ways that emphasise rather than blunt divergent ideas to the social and environmental accounting literature (Thomson, 2007). The trust we place in others is critical to our networks if we are to move from ‘me’ to ‘we’. Personal experience is part of the understanding that drives my work, but so does a shared knowledge of disability equality and much research evidence that informs a whole manner of things relating to the interests of the disabled population. Having an impairment is only a small part of our own tale, a critical part undoubtedly, but the pursuit of shared interests makes us more powerful in joint storytelling. As in other civil rights movements there have been many activists, thinkers, movers and shakers in a disabled people’s voice. What I think defines

us as an anti-ableist is shared struggle for human rights set against vast structural and societal inequalities.

In the social and environmental accounting literature, legitimacy theory helps researchers to look at disclosures but the theory needs more sophistication, which involves drawing on developments beyond discipline (Tilling, 2004). Accountability demonstrates a willingness to first acknowledge and then represent the voice of all groups in society, this willingness is demonstrated by the representation of their interests in their conversations and texts. In other words, an organisation's commitment to uphold the rights of individuals from marginalised groups is apparent in the naming of their interests as an aim at the heart of purpose.

To be accountable, for example, it is not enough to not intentionally hurt women: an organisation needs to have words to describe the discrimination women face and the cultural oppression they are disadvantaged by – misogyny and sexism. Without a language describing the nuance, being nice to individual women has little impact on cultural and social aspects of inequality. The stance of the organisation needs to be intentionally anti-sexist in its practice and vision to address the socio-political matters that also impact on economic ones. As demonstrated by Sustainable Development Goal 5:

While some indicators of gender equality are progressing, such as a significant decline in the prevalence of female genital mutilation and early marriage, the overall numbers continue to be high. Moreover, insufficient progress on structural issues at the root of gender inequality, such as legal discrimination, unfair social norms and attitudes, decision-making on sexual and reproductive issues and low levels of political participation, are undermining the ability to achieve Sustainable Development Goal 5. (United Nations)

Addressing the equality of a specific group with legitimacy, therefore, involves being aware of priorities that are external to the organisation, and being keen to engage in dialogue to redress the specific injustice facing the civil rights of those groups that are marginalised (Deegan & Unerman, 2011). The increase in academic texts from feminist, critical race, queer and crip theorists has added divergent ideas that have enriched and altered perspectives in accounting, adding nuance and originality for the benefit of society as a whole (Klein, 2014; Mouffe, 2014; Coulson, 2016). This, given the textual nature of accounts and reporting, highlights a wish to include alternative narratives to reach better accountability, and presumably address existing epistemic injustice (Adams and Narayanan cited in Gibassier, Unerman, & Bebbington, 2007). Because existing orthodoxy ultimately reinforces the ableism found within oppressive structures of the existing social order, and education also defines the language of accounting, establishing accountability for the profession needs to go further to articulate the impact on the human rights of difference groups (Li & McKernan, 2016). Unfortunately, existing language to define the position of marginalised groups falls short of a fair response to those often identified as the most disadvantaged in our communities (McPhail & Walters, 2009; Gallhofer, Haslam, & van der Walt, 2011). Furthermore, not questioning traditional measures can diminish trust overall, as a veil of rationality obscures the more divergent ideas coming from other disciplines. Taking a radical idea out of context often involves blunting its edges, and ‘domesticating it to the point that the creative potential is often lost’ (Oswick, Fleming, & Hanlon, 2011, p. 328).

1.6.1 Accounts, reports and re-presentation

It is the ability to account for the interests of the disabled population, therefore, that is in question. In the public sphere accountability has ‘two essential aspects, namely doing the right thing (performance), and giving an account of it (reporting)’ (Gray, Owen, & Adams, 1996, p. 45). In relation to the call to address the marginalisation of disabled people, the impact of an oppressive

society as suggested by the Sustainable Development Goals, this would mean acting to address inequality and telling how this is done. As social and environmental accounting research grows, for many the term will need to refer to ‘accounts that extend beyond the conventional financial or economic focus’ (Gray, Adams, & Owen, 2014, p. 46), and include ‘practices like social reporting, sustainability reporting, corporate social responsibility (CSR) reporting, stakeholder dialogue reporting and environmental reports’ (Perkiss & Tweedie, 2017, p. 174). Thereby, doing and telling – the storytelling - can alter the reality of what is perceived to have value (Hines, 1988).

The web motif begins here in the intertangement of life on earth, systems within systems, interlocking and interrelated. The text brings together many webs: the webs of relationships within organisations (Helgesen, 2005), the webs of significance represented in culture (Geertz, 1973), webs tying meaning to words to the action through dialogue (Shohamy, 2006; Pennycock, 2010), the web of accountabilities adding divergent ideas to the assumed neutrality of accounts, the webs of concepts connecting theories to people and their feelings (Hawley, 2012), and the webs of ideas depicting vision and holding anticipation

‘With the right words you
can change the world’
(White, 2015)

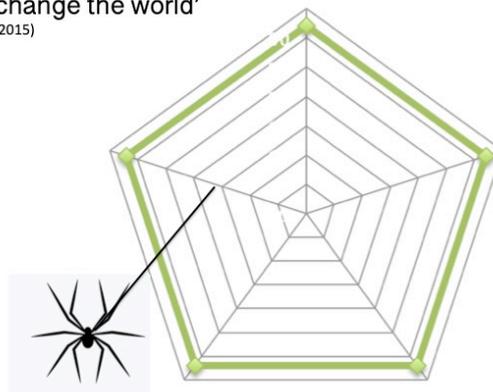


Fig 1.2: Web shape

Emancipation is a core value, if not *the* core value, that many suggest underpins the critical reasoning for social accounting practice (Gallhofer & Haslam, 2006; Dillard, 2007; Gallhofer & Haslam, 2011; Gallhofer, Haslam, & van der Walt, 2011; Gray, Adams, & Owen, 2014). This is why financial calculations and monetary measures may benefit from additional accounts that are

equally distinctive in their alternative value, because '[r]esearch and practice has shown that others, with alternative worldviews, may fundamentally reject that financial valuation can in whole or part be used to represent social impacts. For example, concern has been expressed that the intrinsic value of social and environmental relationships centred on human rights or the value of a life should not be subject to commodification and any attempt at placing an arbitrary financial valuation is inappropriate' (Coulson, 2016, p. 520). This acknowledgment of multiple world views invites the performance and the reporting of additional narratives to those which are traditionally accepted. Some will be divergent and others oppositional, but accounts 'by groups such as campaigners and activists with a view to promoting their causes or countering or challenging the prevailing official and hegemonic position... In broad terms, counter accounting has long been around as a matter of principle and practice' (Gallhofer, Haslam, Monk, & Roberts, 2006, pp. 681-682). Rather than seeking to legitimise the figures within its report, social and environmental accounting practice such as integrated reports 'are promoted as a practice aimed at helping companies address pressing environmental, social and governance issues in ways that enable them to prosper over the long term to the benefit of both their shareholders and society at large' (Eccles & Krzus, 2010). Trust is gained through legitimating dialogues, where the 'preparers even refer to IR as strategic storytelling that allows "the company story to be told in a way that it has not been told before"' (Higgins, Stubbs, & Love, 2014, p. 1381).

1.6.2 Power, language and culture

Thompson states that a narrative is 'a discourse [that] is literally a conversation, but is used to refer to frameworks of language, meaning or behaviour that is contained within certain 'power rules'' (2007, p. 5). In this vein, language policy and disability equality are used as theoretical lenses, corraling words in their context, thus reporting on the power held in conversation. Language policy indicating where and who holds culture, and disability equality the interest of disabled people and

what is articulated by the language of their communities. Both enlightenment and empowerment create the conditions for emancipation according to Thompson's (2007) analysis of Lukes' (2005) work on three dimensions of power. As an oppressive power, conversations or narratives that articulate prejudice, discrimination and inequality, are those that dominate in holding a bias within storytelling. Ableism thus builds cumulatively from the position of the individual, to the group and across society more widely a negative or distorted presentation of the disabled population (Thompson, 2007). Where a narrative supports a structural oppression it reinforces the cultural representation that then influences individuals' ideas. A divergent conversation, in counter-distinction to a counter-narratives, is a dialogue that reasserts self-representation, and empowerment through resistance to dominant oppression - rather than creating personally affirmed or group strength (Diers, 2004; Thompson, 2007). Dominant narratives, and the groups that speak them, maintain their prevailing position, because their accounts hide a complexity that is hidden (Simpson & Mayr, 2010); the unintended result is people habitually collude to maintain the privilege of storytellers (Pease, 2013). An ableist narrative, more specifically is rarely disrupted because it lies unseen within cultures; it would require a significant amount of will, if not energy, for language to stand in opposition to it (Fricker, 2007).

Language policy allows us to view as narratives a meeting of culture and language, held together by words used for meaning. The meaning is guided by a need to express common ideas, and sits above the activities and purpose of a group (Agar, 1994; Shohamy, 2006; Holtgraves, 2002; Schein, 2010; Pennycook, 2010). The way language and culture express power (Agar, 1994) – as liberation and/or oppression and resistance (Freire, 1970; Thompson, 2007) – is developed more fully in Chapters 2 and 3 with regard to the disabled population. Within culture and language, the stereotypes of 'victim' and 'scrounger' have been an established narrative for the disabled population (Joshua, 2017; Hughes, 2015; Michalko, 2002). Narratives are reinforced by ideas

‘occurring in language and through social interaction’, where layers of myth, assumption, and widespread ignorance dominate how disabled people are viewed and how they perceive themselves (Riddell & Watson, 2014).

Disability equality emerged as a type of training, based on theory from disability studies, which was developed to stand in opposition to disability or impairment ‘awareness’ training (Campbell & Gillespie-Sells, 1991). Unlike the medical approach of impairment awareness training, disability equality addresses the discrimination disabled people face from a social perspective underpinned by the social model of disability. Rather than a focus on individual deficit, illness or difference, disability equality considers the ableism underlying disabled people’s oppression and looks at disability in a pan-impairment way. Disability equality exposes a systemic and societal oppression that is reflected in language, prejudiced behaviour, discriminatory practice and unjust policy. The theory also helps stimulate new ways of approaching disabled people’s interest, not their issues, from Community Organization studies rooted in social justice (Marshall & Oliva, 2006). With its origins in the conversations of the disabled people’s movement, it is the closest embodiment/enactment of a political understanding of the culture behind the voice of disabled as a group (Chapman, 2011). From an academic perspective, as a discipline disability studies is critical, as evidence suggests that workers are more likely to trust their own lack of knowledge based on hearsay than to seek out alternative knowledge that could discredit their own feelings (Gladwell, 2008; Ferguson & Nusbaum, 2012). With particular regard to the voice of people with learning difficulties, the message from activists is clear: ‘The law and policy as it affects people with learning difficulties – our lives are often ruled and directed by laws and policies that we have had no say in. One of our mottos is “nothing about us without us” and we’re pleased to say that, these days, UK and local government usually tries hard to listen to our points of view’ (People First Scotland). However, this stands against common assumption that disabled individuals are generally

assumed to be non-deserving fraudsters or malingerers, disabled people have more recently been viewed as superhuman (Crow, 2014; Ryan, 2019), freeloaders or victims (Barnes, 1991; Hughes, 2015; Burch, 2018). Austerity has been identified as a contributing factor to the atrocities in human rights erosion. As the Huffington Post UK coverage of United Nations Convention on the Rights of Persons with Disabilities quotes: '[c]hanges to benefits and care under austerity have led to the disabled being increasingly marginalised and shut out of society' (Sommers, 2017).

1.6.3 Stories and textual evidence

Texts are used to answer questions of legitimacy here because they serve as public accounts in mainstream debates. A global storytelling in which disabled people's interests rarely feature, more noticeably in areas where workers have an authoritative voice, are rarely informed by the issues facing, let alone the more aspirational interest of disabled people (Kafer, 2013). In the United Kingdom, where the voice of the disabled population is often represented by Disabled People's Organisation's as the language of self-representation chosen for its activist intent. The words used in this document reflect this choice, because they align with disability studies and, as will be explored in chapter four, stand against a broader storytelling that remains lacking in disabled authors. The research looks at culture, acknowledging personal experience, but looks beyond it at the public shared texts that answers questions about storytelling. Who are the tellers, where is power held, and what language is used to present dominant ideas? While identity is a wholly worthwhile focus of interest, culture is not the same: both are influenced by beliefs, stereotypes and on feelings that differ locally, nationally and globally but an organisation's culture is not necessarily the sum of the individual values held by members within it (Hofstede, 2001; Michalko, 2002).

Could the stories told in accounts come to be considered as multi-layered narratives, a hybrid practice 'that builds on the strengths of accounting, such as robust quantitative evidence gathering,

relevance, materiality, reliability, comparability and assurability, to translate the sustainability discourse into a ‘language’ understandable to organisational decision-makers’ (Thomson, 2014, p. 19)? Individual emancipation is respected in an equitable culture in which human rights win in opposition to majority decision, and their subjectivity and universal application link them to wellbeing through economic governance (Gallhofer, Haslam, & van der Walt, 2011). Thus, governance links human rights’ violations to accountability and the emancipation of individuals from marginalised groups as they ‘translate neo-colonial policies into practice with the consequences of reproductive and cultural genocide and ecocide’ (*ibid* p. 773-774).

1.7 The storyteller

"We value stories because they are like reports of research projects, only easier to understand, remember and use" (Klein cited in Denning, 2005, p. 178)

I have been an Equality and Diversity facilitator and consultant for 20 years, specialising in disability equality, educational leadership and social justice. For much of that time I have facilitated training, and I am repeatedly struck by how often other workers reject the idea that disabled people face a named oppression. I am often told by participants that I am wrong about the scale of the injustice disabled people face. It is as if they trust their own experience rather than attempting to confound their own assumptions and accept the research evidence or the working wisdom I offer them. The power in a language we could share is upset in that moment, their voices louder than mine, because their ideas are supported by a wider narrative steeped in myth and misrepresentation (Deal, 2007; Crow, 2014; Hughes, 2015). Rather than explore new meaning in the language I offer them, they appear happier to tell – and re-tell – their side of a story. This allows them to say how disabled people *should* act in order to solve their issues. Often the dissonance is so great a few participants cannot see beyond their own thinking, or their behaviour, even with ableism defined on the slide before their own eyes. See Figure 1.3 ‘Ableism is...’ PowerPoint slide below:

Ableism is ...

... an all-too-real issue - discriminatory, oppressive or abusive behaviour arising from the belief that disabled people are inferior to others. 'Institutional disablism' describes a whole organisation's (dis)ablist attitudes, practice and culture.

(Miller, P., Gillinson, S. and Parker, S, (Demios, Scope & DAA 2004)
[Disablism: How to Tackle the Last Prejudice.](#))

Figure 1.3: 'Ableism is...' PowerPoint Slide

Disability equality is a defined subject area based on disability studies, which is defined in section 3.6.1. In my first training job at Disability Equality in Education, the induction lasted two days and included presentations and activities. Soon after this, I was tasked to write a chapter for a handbook introducing key ideas of disability studies and their relevance to education. I remember how inadequate I felt, and have only dared approach the task again from a more academic perspective, having worked with the key ideas for 15 years with hundreds of workers (Chapman, 2011). A decade ago I started learning about leadership in education, spurred by the prevailing interest in wellbeing and social justice which arose from the 2003 Every Child Matters initiative after Victoria Climbié's death. Since then, I have worked in the United Kingdom, in Canada, the United States and Australia, where I gathered much of the ethnographic insight that I bring to this research. Without this high degree of gallivanting, I would be without the cultural understanding that helped me place the empirical site on a global landscape.

I was brought up in France, years before the Education Act (1981) that prioritised a right to full citizenship, therefore for *handicapées* the moral statements directed at citizens within communities

did not apply. Disabled people were institutionalised. I escaped, by the skin of my teeth, in a bizarre interview with six professors at the Sainte-Anne Asylum in Glacière, where I was first labelled a *crétin*, but then reappraised as ‘school ready’ – after my mother was allowed to explain I did not *yet* speak French. Less than a year later I knew words my mother could not look up – gifted! This sadly is not ancient history, for many the legacy persists, and is a reality for many disabled people. Fit in or ship out. Then, for most teachers it meant ignoring the needs of those who could not keep up, we were allowed to watch, but not participate. Ironically, the 70s was a time when people were flying to the moon and bricks were flying at the establishment - it was a moral, cultural and social turning point in France’s history. Around me, people talked of revolution, in a non-political movement that would ripple down the years; it was a show of intellectual strength against capitalism, consumerism and ageing institutions. Youth at that time held power, and patriarchy was the authority under challenge. In schools, racism was on the hidden curriculum, students chanted and wore badges declaring: ‘*touche pas à mon pote!*’ [‘Don’t touch my mate’]. In the streets, marches echoed to this cry, a stand of unity, fraternity and justice, citizens walking with purpose in solidarity with their North African peers. It was a time of positivity and possibility, social change, great energy and deep questioning: the *anciens régimes* were being held to account by the population. In Boudieulasian terms these last paragraphs state the field, explain the capital and frame the habitus that maketh the researcher (Grenfell, 2012).

With this in mind it may be easier to see why I could not understand why disabled people’s voices did not have a language similar to those emerging from other civil rights groups. There were no words framing ableism as equivalent to feminism, sexism, homophobia, or white privilege, despite an era of rising social awareness, disability had no name, no voice, and little common history.

1.8 The research site: ReShape and Scotland

Set in the South West of Scotland, ReShape (name changed for anonymity) is a unique empirical site. It was created to provide a community living solution for people leaving institutional provision, thereby restoring more fully their entitlement to human rights. ReShape followed the philosophy of the Independent Living Movement, which ‘was started by people with physical disabilities, but it was soon joined by people with intellectual (or learning) disabilities, people with mental health problems, people with chronic illnesses, older people’ (Squire & Richmond, 2017, p. 2). For the research, it was significant that its clients could be assumed to be disabled people, as all have complex requirements, without the need to ascertain whether each individual assumed ‘disabled’ as their identity. ReShape helps its clients reach a number of outcomes based on human rights, by leading their own teams and having a choice in the support they want. ReShape is a leader in its sector for its innovative and high standard services, and has received awards from The Charity Awards, The Scottish Charity Awards and The Scottish Social Services Awards. Foremost ReShape supports people with Personal Budgets to create individualised packages in order to purchase the help they need, plan for activities they want and move into a fulfilling future and support dreams and aspirations to become a reality. ReShape workers are enablers, working alongside an individual and the people who know and care about that person. The organisation place each person at the centre of their support plan; listening to what they say and supporting them to be in control as much as they can or want to be. Individuals are supported to recruit their own staff team matched to their needs and interests – a philosophy based on human rights, which are key to delivering the right support.

ReShape was created specifically to help people get out of institutions, and to support individuals in their localities, supported by their families, friends and local services. ReShape’s success has been built on helping those most isolated gain independent living – freedom, dignity and control. This

was ground-breaking 10 years ago, as for most people with significant impairments life was characterised by misery, humiliation and abuse in institutions and ‘hospitals’. As stated by Brisden Independent Living delivers on human rights because: ‘We believe that the choice of independent living is not a privilege conferred on us by a generous society, but is the right of all individuals, regardless of disability, to live in the community’ (Brisden, 2007, p. 178). Working initially with small numbers, ReShape proved that independent living was not only possible, but was also a cheaper long-term option. Furthermore, costs of support often reduced as disabled individuals gained greater independence over time. Few organisations get to begin with a wholly alternative approach, and from an unconventional starting point with a whole different way of structuring financial flow into and beyond the organisation. This ‘pot model’, more fully outlined in section 7.1.3, where the organisation is paid by each of its clients, allows services to be crafted individually, which means hours can be filled by different support plans to suit a number of outcomes. For many years, this in-built flexibility has been ReShape’s great advantage. However, while being small and nimble has often enabled ReShape to respond before the impact of policy changes, the ‘pots’ do need filling. Where other organisations have struggled to adjust operationally to funding cuts, the gigantic shortfall imposed by a government austerity drive more recently has imposed increasingly greater strategic demands on already stretched systems. Funding cuts have led to many larger organisations folding completely, resulting in deaths which have been linked to a ‘punitive welfare retrenchment, the stigmatisation of being a recipient of benefits, and the internalisation of market logic that assigns value through ‘productivity’ and conceptualises welfare entitlement as economic ‘burden’” (Mills, 2018, p. 302). At ReShape, where once financial security could be built in to its ways of working, ever-diminishing budgets are presently causing more and more hardship for both clients and workers, as they have to all across health, social care and disability sectors.

1.9 Methodology first

The unusual chapter sequence arose from the research constraints, because in mapping the terrain - the knowledge base – it was found that the voice of disabled people is often omitted or misrepresented in text. Chapter two therefore articulates this, explaining epistemic injustice as the ableism in society. Chapter four explores this anomaly, and explains how a void in texts misrepresent matters linked to portrayal of the disabled population. This critique gives an outline of the character of misrepresentation, as a distortion in storytelling: the narratives of injustice. A mapping of the literature review, therefore, was not possible this explanation about the silencing of the disabled population and its impact on the textual world.

There were a number of issues key to understanding of the marginalisation of disabled people (and therefore the way texts were biased in their representation of disability) that needed to be explained before the analysis. The methodology chapter explains why, despite its growing strength, the Disability Movement has struggled to share an articulation of ableism beyond its networks, including in education the boundaries of disability studies (McRuer, 2006; Fricker, 2007; Kafer, 2013; Goodley, 2014; Oliver, 2016); and why everyday representations of disabled people in society are generally negative and damaging (Barnes, 1991; Michalko, 2002; Titchkosky, 2009; Hughes, 2015). The absence of evidence (primarily in academic literature and more widely across research disciplines) explains the specific methods sought to redress bias in accounts in the textual analysis. Furthermore, as stereotypes and misrepresentation abound, they creep into all societal narratives that invariably influence research writers. For this reason, the methodology and methods chapters were used to give an explanation of the impact of marginalisation on storytelling and text. By using an analysis on texts relating to human rights, in line with Sustainable Development Goals, Chapter four then outlines the characteristics of an identified silencing imposed on the disabled population, and proposes that the absence, or misrepresentation of disabled people's authority in

texts, in myths told and re-told about disabled people are repeated in countless aspects of public life. The disabled population's silencing is characterised by a lack of balance in the way their interests are addressed, if at all, in written accounts. The misrepresentation has been recognised as an epistemic injustice running through storytelling across the centuries (Beauchamp-Pryor, 2012; Kafer, 2013; Carastathis, 2016; Lightbody, 2017). Identified as narratives of injustice, these five aspects of disabled people's silencing are used in following chapters to provide a more legitimate representation, as described fully in Chapter five – the web of accountabilities. An exploration of this reinterpretation was deemed important to explain the use of the literature review as an iterative step of the research rather than simply the mapping to precede it. In other words I explain why Jean's story becomes twisted, if told at all, and how in the past personal boundaries have been transgressed in the production of research accounts **about** disabled people like her.

To say social and environmental accounting literature was sparse would underplay the utter void I encountered. I had expected few texts and little by way of historical voice in the academic, peer-reviewed writings, but the absence was far worse. Sadly, without a textual record it was hard to refer to a trustworthy knowledge base. There was no reliable narrative to indicate how hard inequality is to bear for the disabled population (Touchet & Patel, 2018), and why it is becoming increasingly harmful to them (Hughes, 2015; Scarlet, 2015; Adams, Luanaigh, Thomson, & Rossiter, 2018). From the social and environmental accounting perspective more specifically, a belief in personal failure, strengthened by a rise in positive psychology (Sang, 2017), has added to the banalisation of injustice, an acceptance of growing poverty to which there is no visible rise in moral outrage or righteous indignation (Dejours, 2014). And while emancipation presupposes that the voices of its subjects exist, many groups have historically been excluded and oppressed through a variety of offensive 'mechanisms of silencing, suppressing and censoring' (hooks, 1989, p.16); and in this 'culture of domination, power relations are a means of silencing particular voices, thus

within such an historical and cultural context finding a voice is an essential part of the struggle for freedom' (Barton, 2005, p. 309). All of this meant that future storytelling was on shaky ground: I was going to find it hard to speak with evidence-based knowledge and thus accountable to the disabled population. Like any activist, every disabled person is not required to be well-versed in politics, but the absence of reference to an existing knowledge base – disability studies – was an issue if the emancipation of marginalised groups is a critical question within the role of accounting for society and the environment (Gallhofer & Haslam, 2011).

1.10 Group authority and narratives of injustice

As Chapter 2 explains, the gap with regard to disciplines outside disability studies is characteristic, once identified as narratives that are warped in their presentation of a voice without authority. Despite growing evidence, for example The Learning Disabilities Mortality Review Annual Report 2017 states that 'people with learning disabilities die, on average, 15-20 years sooner than people in the general population' (Norah Fry Centre for Disability Studies, 2017, p. 5), and according to the Government of the United Kingdom, this inequity in its accommodation to larger scale unsustainability and in far reaching areas of social policy is hitting disabled people hardest according to the disabled people and economic growth debate on Brexit on 22 Feb 2018 (UK Government). Ignorance, or wilful denial, is based on centuries of institutionalisation stretching back beyond the industrial revolution (Slorach, 2016); that made disabled people invisible as a marginalised group, and hid the inequality and hardship they faced as members of the population (Marmott, 2015; Pickett & Wilkinson, 2017). A lack of nuance, more specifically around definitions of sustainability, hides who is hardest hit by unsustainable growth in mainstream media from public discussion. Disabled people, categorised as non-workers, are then perceived as faulty or in need of expert care, which helps hide the significant negative impact of environmental policies in social and environmental debates on them (Fenney Salked, 2016).

While disability studies offered robust evidence of the personal experience, working wisdom and academic evidence provided with disabled people's voice, academic literature (like more generalist writings) spoke of what disabled people were thought to lack. Finding a voice that represents a population in text is difficult - a fact over which I was to labour long and hard.

Epistemological injustice is explored in Chapter 2 as it frames the challenge to define the knowledge base and analytical tools presented in Chapter 3. Post-humanists remind us of the complexity of human nature - the messiness of life outside the more binary continuums of academic debate, important when conceptualising disability as a widespread experience despite its fringe status. This means that, as Goodley notes, 'disability is not a minority nor a peripheral issue: dis/abled people all face the threats of an increasingly punitive and governing ableist society' (Kumari Campbell, 2009, p. xii). This section has outlined critical factors affecting the literature review that follows in Chapter 4, but is essential in explaining why a peer-reviewed textual history was problematic (Saffer, 2017).

Given the restrictions of time and money, the process can be seen as having emancipatory values, although it cannot be defined as participative research according to the methodological and ethical challenges of involving people with high support requirements or learning difficulties (Cook & Inglis, 2012; Goldsmith & Skirton, 2015). However, to be congruent with the emancipatory aims, the iterative stages were led by ReShape workers, therefore the storytelling presents the language and culture they share within their organisation (Agar, 1986; Pring, 2000; Townsend, 2013).

1.11 Telling stories

The textual issues in representation, culture and storytelling outlined above, make it easier to explain the constraints involved in the research. These were dealt with by articulating silence and power in order to define evidence-based knowledge to adjust to current injustice. Chapter two explains why a conversation with Jean would not satisfy the aims, not because personal experience has a limited contribution to research, but making private thoughts explicit can be harmful, and most possibly damaging. In contrast, examining culture and language, is more likely to help identify the missing bits – the storytelling – that could give insights into accountability and human rights.

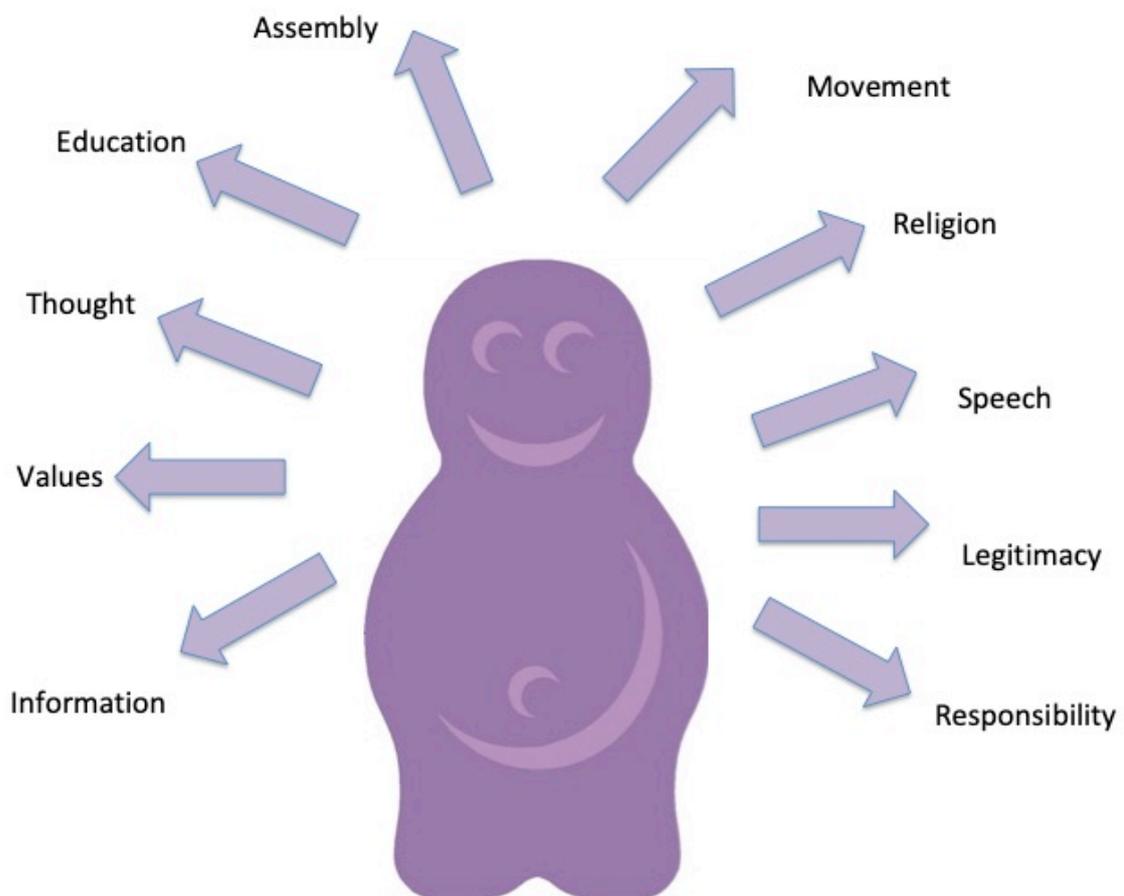


Fig 1.4: Storytelling & human rights

Conversations about human rights are relevant to issues of sustainability and legitimacy, as they *should* represent the interests of the entire population, and therefore include the more specific representation of those currently denied rights they should be *universal, inalienable, indivisible and interdependent* (Equality and Human Rights Commission, April 2017). To put it another way, lack of legitimacy towards the most disadvantaged in society becomes apparent when examining the failure of providing basic needs to those disadvantaged by overall growth in a system unequally assisting those most privileged by its structure. In the distinctive narratives that replace or reinterpret disabled people's voices in conversation and help to marginalise them in community life, in areas of justice, employment, transport, leisure and education (Equality and Human Rights Commission, 2018). Ableism frames storytelling, therefore impacting on identity and the lack of visibility of disabled people in culture in ways that perversely make individuals stand out while as a group they can be ignored (Riddell & Watson, 2014). More specifically Chapter 2 explores the way academic texts written by disabled people in theoretical discourse is rejected in favour of expert and impairment focused or individual – often personal – accounts that reinforce stereotypes and ableist ideas (Brown & Leigh, 2018). To compensate, the use of non-peer reviewed literature in Chapter 4 adjusts for ableism, as a wider epistemic injustice (Fricker, 2007) that silences disabled storytellers, and misrepresents their marginalisation within academic life (Nind, Sheehy, & Simmons, 2003).

Building in this adjustment to an existing textual world, the iterative-interpretive methodology reflects the belief that storytelling is neither objective nor subjective, but creates a reality from which truths can be analysed and meaning made (Agar, 1994; Benedict, 1934; Robson, 2011). As Madden says, the 'task for ethnographers is to tell the explanatory stories in such a way as to find a middle road between the inductive and the deductive, between the particular, bottom-up theory and general, top-down theory' (Madden, 2010, p. 18). As the methodology explains, the text aimed to reflect the leadership within the disabled people's movement by naming those within disability

studies with research evidence, adding practitioner wisdom experience and personal experience of disability in **that** order, to ground knowledge in an activism that reflects paradigms of social constructionism and co-production (Cahn, 2000; Mauthner, Birch, Jessop, & Miller, 2002; Hammersley & Atkinson, 2007). In addition, to acknowledge intersectionality, the literature reviewed also sought to draw on perspectives from feminist theory, crip theory, and critical race theory (McRuer, 2006; Butler, 2006; Kafer, 2013; Carastathis, 2016; Bhopal, 2018), because the disabled population includes diversity. Ethnographic research allowed an alternative to the myths in storytelling outlined above, because it ensures that ‘disabled people should be considered experts on their own lives, needs and feelings, and therefore, that those who do research with disabled people should allow disabled people to play an active part in shaping the course of research projects’ (Stone & Priestley, 1996 cited in Davis, 2010, p. 192). Using crip theory to define ableism, the authority behind an ableist gaze, allowed me to remain anchored to the social model of disability - an important distinction, as traditional research has been about disabled people based on non-disabled researchers interests (Oliver, 1997) - and to be as empowering as a small project can be. The aim was to gain knowledge in a way that brought together personal experience (Beresford, 2003), practitioner wisdom (Freire, 1970), and research evidence (Oswick, Fleming, & Hanlon, 2011; Goodley, 2014) that would be aligned to the interests of the disabled population. As narrator, not author, and ethnographer I was sensitive to actions and context, both reflective and reflexive in the telling of a story, hoping the emergent narratives would lead to deeper levels of reality (Speth, 2008; Madden, 2010; Punch, 2014). Thus the iterative loop, makes tacit the knowledge ‘that is said to inform, embed, shape, and account for the routine and not-so-routine activities of the members of the culture’ (Spradley, 1979, loc 360). In the field I used my heart and hands [feet] to join in shared activity, using a selection of methods that follows reflect a belief in culture as shared understanding (Schein, 2010; Agar, 1994) - a language creates a co-produced reality.

1.12 A tale of many languages

As figure 1.5 illustrates, there are three main parts to the thesis, with the storytelling tracing a far more linear path than the journey that took me from chair to field - and back again – many times over lots of months.

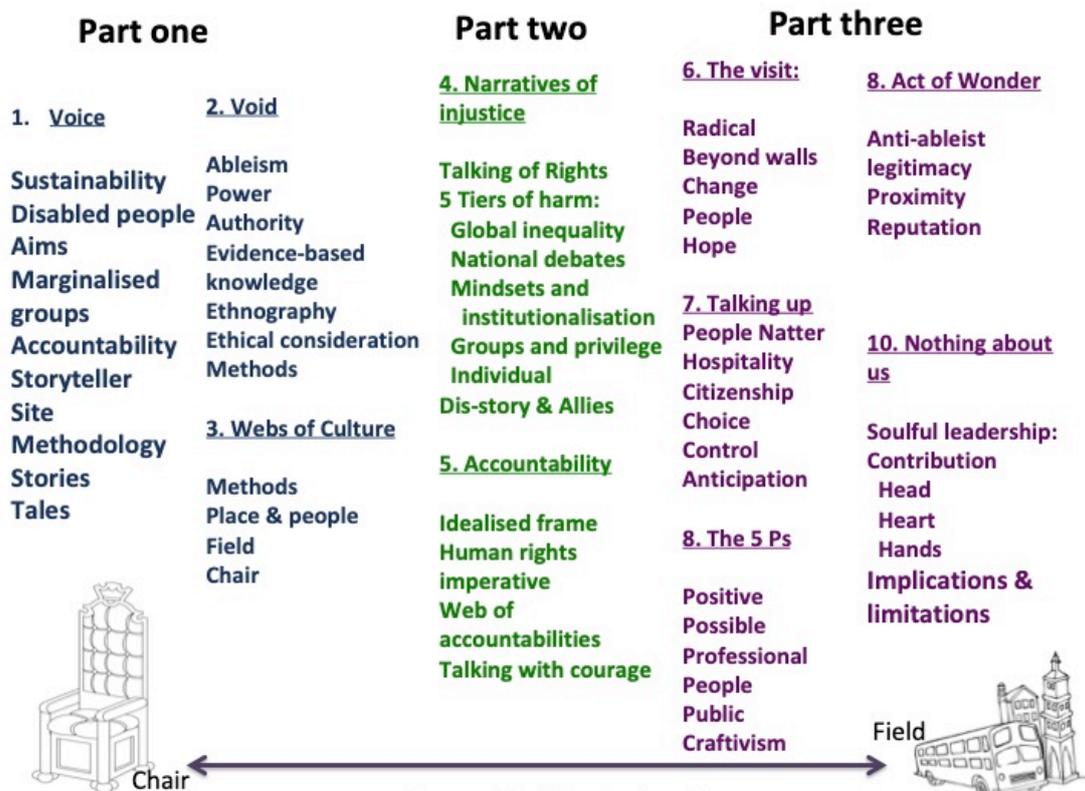


Figure 1.5: Thesis structure

1.12.1 Part one: emancipatory research

In Part one, the introduction, and chapters on methodology and methods, deal with the silencing of disabled population as authors in a global story. A definition of ableism is put forward, to explain the lack of power causing constraints regarding authority, accountability and legitimacy in the research. The second chapter also introduces the misrepresentation of the disabled population in accounts making it a group with specific interests. This explains the difficulty in working with

existing texts, and the adjustment taken with evidence-based knowledge, to reach a storytelling that considers research evidence, working wisdom and personal experience more fully. Chapter two includes the ethical nature of this research, an iterative process that puts the voices of others at its heart. It acknowledges wellbeing as its primary concern, the research second and the discipline third in a hierarchy of ethical responsibility (Madden, 2010). Chapter three goes on to outline the methods used, and reasons for them within an intersectional approach, with ethnography creating meanings in conversations that hold intent, reality and ambiguity. By moving backwards and forwards between chair and field, the researcher assumes a led position, not author but narrator: it's my story but *of* the lives authored by others (Poole & Morrison, 2003; Townsend A. , 2014).

1.12.2 Part Two: narratives, accountability and storytelling

Chapter four is a textual analysis that identifies narratives of injustice, serves as a literature review that which can be compared to the reconnaissance phase in action research (Townsend A. , 2014). The chapter explores how the history of disabled people, has led to their institutionalisation and marginalisation, and their miss-representation in society's storytelling. The analysis explains why I sought voices from known individuals, blogs and social media, to reflect the 'affection, love, disappointment, anger, intrigue, repulsion, belonging and culture shock' experienced in communities across the glob (Madden, 2010, p. 179). I highlight a lack of terminology, and an associated struggle with knowledge sharing that fosters a confused, contradictory and reductionist view of disability. The chapter it aims to give the research a global positioning by providing a time-framed snapshot which explains the present-day context.

In Chapter five, a human rights imperative provides the grounding of an idealised framework - the web of accountabilities – to be used as a way of illustrating the scope with which dialogic action can extend legitimacy within organisational conversation. The web motif, a radar, whose axes

represent the types of dialogue that counters the misrepresentation identified in the narratives of injustice. The axes represent organisational storytelling as a path to including the interests of the disabled population in strategic accounts. As depicted below in Fig 1.5, my own of understanding of accountability started as an almost binary line, with the financial end overly developed and the political end blunted by shallow thinking in the terms of a sum-game. The research led to a far more complex and nuanced view that encompassed five cultural and societal conversations that addressed the tiered layers of harm found in the analysis of texts.

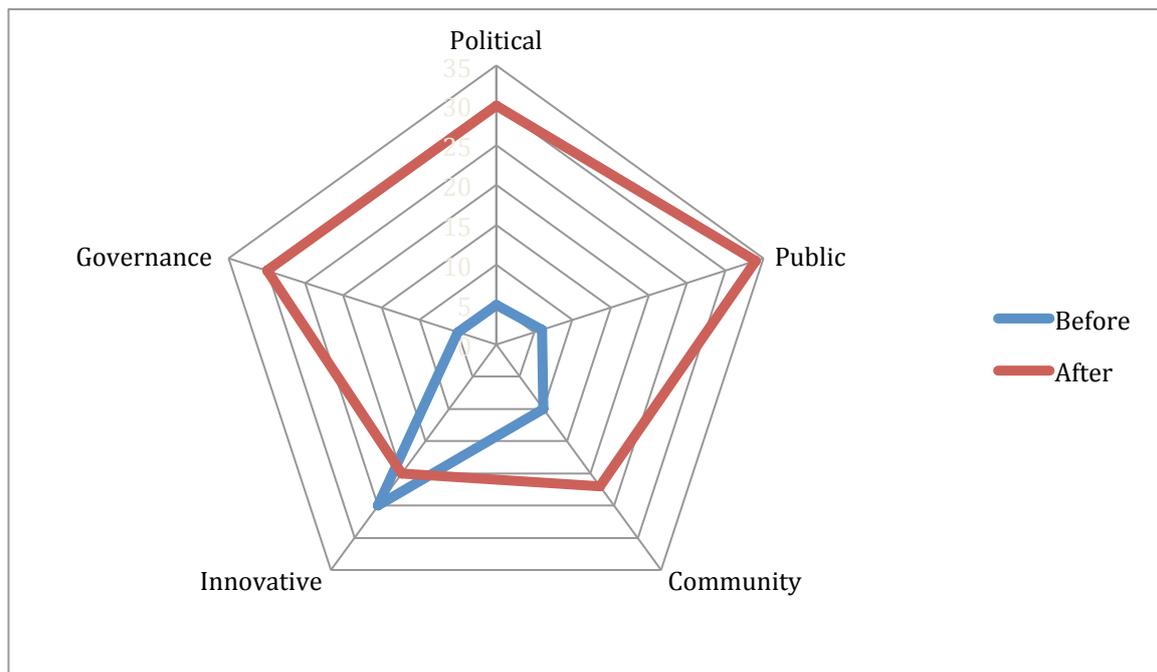


Figure 1.5 Web of Accountabilities – scope of knowledge before and after the research

The figure also shows that as the interests of the disabled population become more real to workers within an organisation, they become more articulated in language and embedded in practice. This mirrors what Gallhofer and Haslam have stated about accountabilities based reporting that would help ‘encourage and stimulate further engagement towards the realisation of a more emancipatory accounting in a more emancipated world’ (Gallhofer & Haslam, 2006, p. 116). By redefining accountability as conversation about human rights, legitimacy is placed in the organisational

reporting practices and the accounts they help create, through the craft and the activism that guide a response to the disabled population as a *named* group within society. Better understood as an ability to account *with* rather than *for* that named population, storytelling is then a production of accounts that includes sought-after groups with divergent voices (Mouffe, 2014); the web of accountabilities is a touchstone for what anchors an organisation's emancipatory dialogue.

1.12.3 Part Three: the field, the chair and words of wonder

Chapter six starts with a description of the organisation, based on visits, in which the language and culture are described. The story told presents a divergent account, not an alternative one to traditional services of the same type. As such history is rewritten with every telling, and authoritative knowledge is recreated in the doing and the being of the art of storytelling (Oliver, 2016). In Chapters seven and eight, I reflect on the language and culture experienced at ReShape, with the web of accountabilities to frame it, the emergent themes supporting the wellbeing of the disabled population are presented as an opportunity of investment. I draw links back to moving beyond compliance, to a values-driven ethical commitment, and use legitimacy theory to support an articulation of a social contract that includes the consideration of all civil movements, of which disabled people are but one. Part Three ends with a loop back to ideas of community, wellbeing and citizenship as a societal conversation - dialogic action intended to draw together different voices and groups of power in order to achieve change (Sennet, 2003). With reference to the narratives of injustice, the organisation's culture is shown for its ability to articulate, deflect and mediate the harm imposed on disabled people. The final chapter discusses the applicability of the findings. The analysis iterated from field to chair in a reflective-reflexive pattern. As layers within layers of narratives were exposed, themes emerged that led to a deeper theorisation, but these were always driven by the workers at ReShape and I sought to capture in my words the language of their worlds. For those familiar with disabled people, their families and community the story is old news.

However, I am constantly surprised by those totally unaware of this narrative, the troubling and courageous story of so many disabled storytellers.

Different writing styles provide a contrast in voice along the journey. Most chapters are preceded with an interlude, in italics to denote a spoken voice telling the story of Jean the human face of the storytelling. The difference in style between the organisation's workers and myself became less pronounced as time wore on. Therefore, inspired by van Maanen (1988), I write from different positions in each part, so the writing style changes in parts one, two and three - with chapter six being the most journalistic to make it come alive for example. In part one, the use of 'I' denotes the individual view I held at the start of the journey, a confessional style to indicate more solitary steps on a long journey. In part two, I use 'they', to hide identity, and to qualify as an outsider in my description of ReShape's culture. For example: "They gathered in the kitchen". In part three, I use 'we', although I was not 'native', I became less of an outsider on the inside of the organisational fence. My intention in using pronouns this way is to highlight a drift towards co-production, to a more central position in the organisation's conversation my account becomes a shared narrative. This also helped accentuate the nuanced subjectivity in each phase of the storytelling. While being mindful that in line with an ethical stance I am always more narrator than author (Mauthner, Birch, Jessop, & Miller, 2002; Townsend, 2014).

1.13 Stepping forward

This chapter has set the scene for the research, by outlining its aims within the context of a wider conversation about accountability, human rights and legitimacy. The aims were introduced as an exploration of the voice of the disabled population in texts that hold power within society's storytelling. The researcher's position explains the passion, motivation and desire that fuelled the work. The uniqueness and importance of the empirical site is explained, as an outlier in its sector,

and renowned for its award-winning practice. The bias in existing textual evidence is touched on briefly, to explain why the methodology precedes the literature review with its analysis of the way disabled people's interests are distorted in larger debates. These distortions, or tires of harm, inform the structure of the framework introduced as a web of accountabilities with as human rights imperative. The legitimacy the web supports, an activist craft, is presented as dialogic action that secures an articulation of specific dialogues within storytelling; one used to identify fluency about human rights in mainstream debates. The following chapter explores power and authority with regard to the absence of disabled people's voices in knowledge creation. I define my own subjectivity in order to place its significance for the interpretation of culture from a disability equality perspective – 'the gaze' in ethnographic terms. The chapter also explores issues of ontology and epistemology, by offering an exposition of its bias, and an alternative adjustment for evidence-based knowledge. This weighting helps ground the methods in the following chapter.

Interlude

There is a growing wealth of accounts telling of personal stories similar to Jean's, despite the growing evidence that hardship is imposed disproportionately from beyond her experience. Sadly, later has not informed former, and Jean's words are often framed in a storytelling that distorts her story. Research texts often tell us that her testimony is not to be trusted; so she is not taken seriously as the author of her own story. Denied access to education, Jean has few words to tell of her place on the planet. Neither should she need to talk her agony, whereas the workers that come into her life have a duty to – by law!

So how can those who need to know her story hear her words? Imagine four people at a table, a worker that provides support to disabled people, a teacher of disability studies, and a relative of a person with an impairment. Which person is in the best position to tell you about Jean's life? The worker will tell you that Jean's rights are central to their job. The relative will tell you that Jean's experience is that of many, she's heard stories on networks of other people who fight tirelessly to ensure their family's rights are met. The researcher will be able to define prejudice, discrimination, and inequality. She will tell you that Jean's privacy is at risk, as her words can be used without care in the stories others. Together, they will say that stories have been told – and re-told – but remain ignored.

Absence of evidence isn't evidence of absence.
Carl Sagan

Chapter Two

Into the void

2.1 Ableism: a silhouette of silence

This chapter outlines the considerations and constraints imposed on research into the culture and language that are oppressive to disabled people. The first three sections more specifically present issues of ontology and epistemology that need to be addressed before methodology or literature can be discussed. An alternative to positivist experimental science is provided here by an interpretivist-inductive methodology in which ‘researchers cycle back and forth between process theory and process data to produce process knowledge’ (Orton, 1997, p. 419). As queer, feminist, indigenous, and post-colonial models of science have, in complex political environments, linked activism to culture and society, anti-ableist theory through a crip-gaze opens up additional spaces for resisting the more traditional and narrow, hegemonic frameworks (Denzin, 2010; Denzin, 2017). Moreover, as the aims call for a type of qualitative evidence that denotes a social justice orientation, by being congruent with a social constructionist perspective of co-production the methodology seeks to be emancipatory (Cahn, 2000; Cha, 1986). A blend of personal experience, research evidence and working wisdom define the evidence-based knowledge that guides the research action, subsequent analysis and theorisation. This means that while a blend of data gathering methods are used, the narrative they shape can be viewed as a negotiated account, told from a specific perspective but not authored by the writer – a shared story (Mauthner, Birch, Jessop, & Miller, 2002).

To fundamentally alter an organisation’s accountability relationships with its stakeholders, accounting systems must use design methodologies that incorporate critical thinking. (Dey, 2002, p. 116)

How does one start to explore the implication of culture on Jean’s world if we do not consider that language can be problematic for someone in her situation? As the introduction explains, fluency around disability, more saliently a nuanced articulation of disabled people’s interests is often lacking in mainstream conversation. For many issues of disability are unheard of, an unknown quantity altogether, while for others the terrain is well travelled and understood in terms of

injustice. In other words, for some disability is in every sense a consideration of daily practice, while for others it is a specific policy held in a file – one that is preferably kept in somebody else's office.

This chapter begins to unpick the lack of legitimacy in research largely undertaken in the past by non-disabled people – those storytellers whose accountability is now being challenged, as many chose to ignore evidence available to them. The next chapter responds more directly to research aim 1: to provide a description of disabled people's silencing. It also answers to a call to satisfy a need for new avenues of investigation and theorisation, as it sets the intervention in an existing research landscape that until very recently was set within an experimental paradigm reported in scientific and medical journals. This research strives to espouse a methodical approach more common to the humanities by answering to the more recent calls for research to be less oppressive to disabled people (Oliver, 1997), that is, accepting disabled people's testimony as a valid truth while respecting the boundaries of private lives and highlighting the exceptionality of truths about disabled people as a group in public debates.

Phenomenologically, the research landscape is characterised by an absence of a collective voice, which places the location of the disabled population outside common boundaries, putting assumptions buried deep within the textual weave of storytelling. Thus, the methodology serves as an explanation for the presentation of the literature review as an analysis. Here a more explicit anti-ableist articulation is used to counter existing injustice, it stands overtly against the assumptions non-disabled research writers demonstrate in their language, in a culture where experimental orthodoxy had to be challenged. A specific definition of academic authority offers a rebalanced articulation of evidence-based knowledge that resists silencing in positive ways. As such it seeks to express a resistance to a wider failure to acknowledge the voice of disabled people as author or co-

authors in a manner more suggestive of an emancipatory continuum. Section 2.3, more specifically, is an articulation that highlights how personal experience has been appropriated by a type of research and has often dominated texts that then frame such discourse as legitimate.

The design follows an iterative and grounded process, with the ethnographic writing used in the tradition of storytelling to capture the organisation's language and culture in text. Stories are understood to do more than transmit information: storytelling tells of value, trust, loyalty and solidarity (Denning, 2005). This iterative and interpretive approach that gathers and makes meaning as it moves along can be compared to the sustainability movement itself (Klein, 2014). It begins with lots of examples of interesting happenings, slowly and progressively drawn together to produce an integral weave. Snapshots of practice are akin to small, quiet particles of change, gradually coming together to take form across cultural divides, organisational boundaries and communities to become a recognised entity: a story (Robertson, 2014).

2.2 Power and testimonial injustice

Where ableism is recognised as power held in the narratives reinforcing the discrimination and the inequality weighing on the disabled population (Kumari Campbell, 2009; Goodley, 2014), it is a story told within texts as a distorted representation of disabled people. This distortion sees the rejection of disabled people as contributors to knowledge, an ontological framing with its own character (Kafer, 2013; Kumari Campbell, 2019). As Snyder and Mitchell have stated 'historically, disabled people have been the objects of study but not the purveyors of the knowledge base of disability' (Dolmage, 2017, p. 4). This means there are specific ethical implications for methodology and methods, because this silencing imposed by the pervasive structural discrimination that drives the injustice reaches within the walls of academe to be reproduced by scholars (Dolmage, 2017). This helped identify why it was important to focus on *how* disability is

talked about, in the same way as wording affects gender, race, and identity in the texts and discourses of education and business (Fairclough, 1989; Simpson & Mayr, 2010; Shohamy, 2006), as words create realities that can harm or inspire individuals, groups and ultimately whole global movements (Shohamy, 2006). Critically, it also helped avoid the direct intervention, where viewed as data disabled people's privacy can be invaded, as it is affected by the language of research (Dolmage, 2017).

Absence rarely evokes interest or emotion, therefore it was difficult to point out this omission that goes unnoticed (Oliver, 1997; Barnes, 2010). An epistemic injustice, named as ableist, can be seen as a space between well-trodden paths, one that is established by the *why* behind the *how* narratives about disabled people are affected by language and culture. Foremost, the absence of disabled authors, signalled by their non-appearance in many narratives, suggests a recognised form of testimonial injustice levelled at groups not individuals (Sandhal, 2003; Fricker, 2007). Can a tale can qualify the author as knower, and also as writer – not author – from a specific perspective. As Denzin states: 'We need interpretive alternatives to positivist experimental science... [to] help improve the status of qualitative inquiry in the current political environment. Likewise, queer, feminist, indigenous, and post-colonial models of science open up additional spaces for resisting the narrow, hegemonic SBR framework' (2010, p. 271).

The social-barriers approach offers us language, drawn from the disability activist movement, that differentiates an essentialized bodily condition limiting function (an impairment) from the disadvantages associated with it (a disability). (Joshua, 2017, p. 309)

As narrator, however hesitant, more than author, the role of the observer-participant follows the anthropologist tradition of Geertz (1973), Spradley (1979), van Maanen (1998), Butler and Mead (2006), using methods that are recognised to have intrinsic political and ethical value, and by disrupting the ordinary and challenging invisible cultural assumptions (Madden, 2010). In the

position of storytellers, those able to tell their own story without hindrance, and those in positions of privilege having the freedom of education, health, employment and housing thus money – if not paid directly – to write. Because legitimacy is secured in the narrator's voice in storytelling, defining authority as a recognisable voice in mainstream debate about human rights. Social capital and shared knowledge are difficult to monetise, and probably would lose in the process, there is no other equivalent or substitution (Giddens, 2013) For the disabled population the story was told by others, and rarely from the feminist position of narrator, generally workers who set the accounts in their language within their culture.

Our opinions, as disabled people, on the subject of disability are not generally rewarded with the same validity as the opinions of 'experts', particularly medical experts. These reproduce the myths of disability through books, articles, lectures and other forms of soothsaying and oracle, whilst also having the good fortune to receive a salary for their effort. (Brisden, 2007, p. 173)

As Nawal Al Saadawi, the Egyptian writer and activist, once wrote while in prison: 'The pen is more dangerous than the gun'. Referring to those holding the pen, by naming those with most power, privilege and opportunity. Disabled people's contribution to history has been ignored, eclipsed by the words of those in employment, because those holding a paid position have been far more likely to published writings and speak public debates (Hall A. , 2016). Furthermore, the power that a paid position can afford also reinforces a western individualist culture that has been identified as framing disabled people in the passive role of recipients, as customers not producers (Slorach, 2015; Runswick-Cole, Goodley, & Lawthorn, 2014; Katherine & Ryan, 2019). Sensitivity therefore, is needed in the research's storytelling, to avoid disabled people being portrayed as heroes, as those 'brave soles' depicted in the rise of the inspiro-porn that objectifies them (Perry, 2016). Avoiding the common tales penned by those most privileged who still hold the power to tell of myths, among the overwhelming number of negative stories that highlight disabled people's deficits, untrustworthiness and malingering (Crow, 2014; Ellis & Kent, 2016).

Stories can have harmful consequences as they silence whistleblowing, the calling out of ill-treatment and violence that characterises human rights abuse. As the following articulation of silencing on a Facebook post from a disabled Black woman makes clear¹:

My heart bleeds about that the number of Disabled People and Older People evicted or family members barred from care homes for speaking up about issues. The whole system is a mess because the first point of call for logging a complaint is with the provider the very same people that you're depended on for your support. Seriously, what a joke, right? Because once a complaint is made about the provider they're going to make the resident's life hell. This is a perfect example to show how many Disabled People are made vulnerable, powerless and placed at a high risk of abuse. Are laws and politics are a complete contradictory if they only there to protect the few. This does raise questions to who is there to protect the voices of the most silent and excluded people within our society?

Figure 2.1 Facebook post: silent and powerless

2.3 Authority: disabled people as knowers

It is our movement, nobody else owns it. We know who we are. (Campbell & Oliver, 1996, p. 124)

Recognising the specific authority in disabled people's voices is important because until 1980 their lives had largely been critiqued by medical workers (Stone & Priestley, 1996), within a world view influenced by the scientific assumptions and religious beliefs of the time (Oliver, 1990). Paul Hunt, an early activist, tells a story that 'condemns the researchers' self-imposed and hypocritical obsession with 'detachment' - hypocritical since the researchers maintained distance from the disabled residents whilst siding with staff and experts. For Hunt claims to 'detachment' and

¹ Permission sought and granted.

'objectivity' - where the context is one of oppression - are inherently flawed' (Stone & Priestley, 1996, p. 702).

While there is no need to identify which individuals do or don't have impairments, the disability movement can be viewed as group within the wider civil rights movement (Morris, 2001). Acknowledging individuals may or may not identify as disabled people, as many will not see their impairment as the single signifier of identity, the group can be understood as comprising activists, campaigners, workers and academics (Shakespeare, 2006). Those within the disability movement have authority in their own story by speaking of their shared experience in a commitment to secure rights. In research, one 'of the cornerstones of the emancipatory epistemology is that disabled people - and not rehabilitation, social workers or researchers - are the true knowers' (Stone & Priestley, 1996, p. 713), and speak of 'an overt political commitment to the development of the disabled people's movement, the use of non-exploitative research methods and a commitment to research which is widely disseminated for use against oppression' (Stone & Priestley, 1996, p. 715). Thereby, the interests of the disabled population, and the multi-tiered oppression – the type of barriers they face, have been effaced by the assumption that disabled people needed care and cure (Brisden, 2007; Barton, 2005). Disability theorists continue to argue that to 'denaturalise forms of social oppression, demonstrating that what was thought of as natural was a product of specific social relations and ways of thinking' (Shakespeare, 2013, p. 12). The philosophical paradigm means the process is repeatable and therefore should remain valid over time and space (Cohen *et al.* 2007). The naturalistic approach means that generalisability is achieved through comparison. However, the interpretative nature of the inquiry also creates the opportunity for positive emotions to support the validity of personal perspective (Kline, 1999 and Crawford, 2009). The study deals not with hard facts but interpretations, therefore, as Lincoln and Guba (1989) state with regard to validity, the naturalist researcher's task is not to provide transferability, but rich and thick

descriptions so that readers may learn and contextualise according to their own circumstances (cited in Cohen, *et al.* 2007).

2.4 Legitimacy: speaking with reference

The language of the disabled people's movement is distinctive and is defined in this section to (a) explain choices in this document, and (b) highlight a choice of words that reference disabled people's interests. Words adopted – sometimes reclaimed - are critical to the group's culture, as language represents an articulation of its interests (Bogart, 2017). One can argue that in defining the many aspects of the oppression disabled people face, words chosen are themselves a demonstration of resistance and activism in a struggle for human rights.

While the word 'ableism' is newly coined, its character is articulated in early definitions of movement politics. For example, online evidence shows that the voices of The Union of Physically Impaired Against Segregation wrote that 'it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation by society' (UPIAS, 1975). More recently, the language used by Disabled People's Organisations reflect a more nuanced wording which applies social model thinking to expressions of group interests. In using these specific words, the meaning demonstrates an understanding of the interests of the disabled population: its people, theories, politics and the interests of a movement.

The terminology used in shared stories where trust is built through the performance of storytelling has led to a disruptive narrative which can be understood as deviant, an act of activism, as feminists storytellers have done previously (Benedict, 1934; Coulson, 2016), or, more simply, divergent from more widely viewed ableist texts **not** written on the authority of the disabled population (Fricker,

2007; Titchkosky, 2011). Standing against the dominance of ideas held within narratives will be explained as power (Fricker, 2007; Thompson, 2007), the voices that dominate society's narratives become the accepted truths we live in (Shohamy, 2006).

Disability is used predominately in research literature to the field of interest or more specifically discipline, for example disability studies.

Disabled people, rather than 'people with disabilities' reflects a commitment to the social model of disability [defined on page 127] and disability studies theory, agreed by the UK disabled people's movement. This term does not however conflict with the definition of disability employed by the United Nations Convention on the Rights of Persons with Disabilities. There are global variations, with groups in the UK speaking of 'disabled people', not 'people with disability'. Not all disability studies literature is clear cut: there are trends and inner squabbles as in all disciplines, but an allied position requires an acknowledgment of group affiliation and a critical approach to major trends. Ideally, dialogue recognises past conversations and the context in which they took place.

People with learning disabilities is used to express a range of impairments, rather than 'persons with intellectual disabilities' or indeed, 'learning disabled people', and references an earlier self-definition of those in the learning disability community. Impairment, while correct in specific circumstances, (such as a doctor's surgery) is private, and can therefore be seen as a metaphor for personal failure, group inferiority and human fragility. As Titchkosky shows with irony in the following, disability narratives are disabling in their imagery:

Blind to the levee issue, deaf to the anguished calls, lame in their responses, and needing to stand up and run with some courageous leadership. This disability discourse serves something other than the interests of disabled people. (Titchkosky, 2007, loc 143)

Deaf people, capital D, is used to signify users of British Sign Language, and the use of **deaf** people, small d, to mean people with hearing impairments who may not use British Sign Language.

This reflects the idea that Deaf people are a community, a group with specific interests, language and culture, and a shared activism.

Non-disabled is used to refer to people not in receipt of disability prejudice, disablism or ableism, this may mean they may have impairments, but m not self-identify as disabled or feel they act in ways that are activist. It is in the use of specific words here, that a respect for the authority of disabled people as a mass of voices articulating shared interest.

Ableism differs from disablism, as it articulates more succinctly the direction of the ideas about being able as oppressive, with the more perfect positioned against others (Kumari Campbell, 2019). Comparable with classism, ageism and religious intolerance, it is the structural and societal assumptions of the norm that non-disabled people take for granted which makes disabled people ‘the Other’. Similarly to people of colour or women, whose colour or gender may cause the reaction of racism or sexism (Pease, 2013; Ahmed, 2017), it is the questioning brought to bear by others that disadvantages the disabled individual looking in the mirror daily. Like Liddiard (2018), I follow Kumari-Campbell’s (2009) definitions of the layered oppression disabled people face:

Disablism: A set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities.

Ableism: A network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human. (Kumari Campbell, *Contours of Ableism: The Production of Disability and Aabledness*, 2009)

Ableism reinforces the structure of the three-tiered oppression articulated by Thompson (2007) earlier – as the dominant narrative to which disabled people are subjected, more specifically the discrimination and systemic inequality not necessarily related to their identity (Davis, 2017; Goodley, 2014). Ableism helps define these more specifically as a capitalist oppression (Slorach, 2016) with an impact on inequality that compounds impairment (Davis, 2017) and weighs most heavily on those who may already experience the personal predicament of being impaired (Oliver, 1990; Goodley, 2012; Swain, French, Barnes, & Thomas, 2014).

Avoiding the stereotypes of disabled people as recipients and articulating the weight and characteristics within systemic and societal narratives irrespective of impairment (Barnes, 1991), ableism also stands against the legacy of political correctness, a multitude of mild terms including dif-abled, dysabled, vulnerable and special, those pejorative and vague euphemisms that elicited a reaction from Disabled People's Organisations to adopt clearer and more nuanced terms (Disability Rights UK, 2018). Addressing ableism as a result of social inequality also allows an acknowledgement of the cumulative negative impact on those most disadvantaged by society's privilege (Layard, 2005; Pickett & Wilkinson, 2017; Rickard & Donkin, 2018), while aspects of culture that impact on marginalised groups, leading to exacerbated pain of those facing a specific hardship or particular disadvantage (Marmot & Bell, 2012; Iacobucci, 2017).

Orthotoxic culture, from orthodox omnipresent and toxic harmful, describes the ableist ideas held in language and culture. Culture, it seems acts on hearts – not minds – we act before we think which explains why unconscious bias resists typical teaching (Fine, 2010), and why people have a storytelling issue when it comes to explaining their own prejudice, because their head is slower at explaining what their hands have already done (Gladwell, 2008). This lack of awareness is explains blind spots, because 'explicitly held knowledge, where you can be reflective and picky about what you believe, associative memory seems to be fairly indiscriminate in what it takes on board' (Fine, 2010, loc 388). One of the reasons given for ignoring ableism is that once viewed as part of a common humanity it challenges the 'them' and 'us' continuum (Goodley, 2014), and rocks the assumptions of so much of what we aspire to in being best, able, attractive and perfect (Davis, 2013; Kafer, 2013). Vulnerability is deeply troubling to many because it challenges a deep-rooted sense of self-worth, tied up in being normal, independent and able - perfect (Brown, 2012). Despite orthotoxic occurrence its impact is rejected, and those who mention it become the problem (Ahmed,

2017). As posthumanist scholars note, ableism is seen by so many as unremarkable, the cult of the body beautiful is so deeply rooted in many societies, that the transgressions that solicit rejection are only beginning to be understood (Goodley, 2018).

2.5 Evidence-based knowledge and anti-ableist intent: re-balancing voice

Anti-ableist intent is introduced here as a way of adjusting the ownership, production and sensitivity to writings about research and knowledge. The case here is to present evidence-based knowledge as it could be if existing research acknowledged disabled theorists, by including the voice of disabled authors more equitably in its narratives. The characteristic intent is also one that disrupts the weave of existing ideas in culture more widely. Thus, the proposed balance will weight against current trends, and will not be need when injustice disappears,⁰ and evidence-based knowledge gives voice specific to disabled researchers or researchers in allied roles. An allied role is defined as one adopting disability studies in the same way men may adopt feminism, that is, without needing to argue a case for the identity of the researcher, so that values within knowledge production are underpinned by honesty, fairness, objectivity, reliability, scepticism, and accountability. This equitable blending also means many domains can be used together in ways that secure broader dialogues – not reductionist ones (Oswick, Fleming, & Hanlon, 2011). This is important because one cannot ‘fully understand the results of a given data set without knowing the historical, social, cultural, and discursive fields surrounding the data’ (Davis, 2013, loc 2648). In addition, defining the authority held by the voice for disabled people as a group in research has the double duty of explaining my own ethnographic perspective and sensitivity. An academic authority of disability activism is articulated here by ‘being’ in the role of ethnographic researchers (Madden, 2010), the result of which is a text that articulates evidence-based knowledge which can be explained as a

balanced mix of personal experience, practitioner wisdom and research evidence (Stuart, 2017). See Fig 2.2 below:



Figure 2.2 evidence-based knowledge

In social research truths are relative, for there are many realities; so in the role of the researcher, I also aim to define my own sensitivity as a crip-gaze. Neutrality is all but a relative possibility in a complex world, especially in a global context where intertangement prevails. Reality is subjective, as moments are perceived differently in time and context and will alter according to the life experience and expertise of the observer. This defines a voice speaking with legitimacy about disabled people's interests as one that blends civic, work and research narratives to produce a text that is accountable to the disabled population.

2.5.1 Research evidence: disability studies

...on the experience of disability, history is largely silent, and when it is discussed at all, it is within the context of the history of medical advances. Just as women and black people have discovered that they must write their own histories, so too with disabled people. (Oliver, 1990, p. 67)

A research narrative that includes the voice of disabled people is lacking because research has for many years been applied to problems *assumed* by the non-disabled population (Aikaterini Malli et al, 2018). Disabled people's predicament is largely dismissed as illness, thus necessitating personal responsibility, not societal concern (Davis, 2013). This demonstrates that disabled people's interests, although being faced by society at large, are easily ignored because of their complexity (Lightbody, 2017). To counter this, the voice of disabled people is required, however equally, through their academic enfranchisement within disability studies. Disability studies theory adds detail and nuance to a wider shared narrative, increasing the blending of ideas in other disciplines addressing society's interests. The use of research from disability studies add validity an ongoing public narrative towards legitimacy.

If the criterion of usefulness were adopted, we should have some reasonable hope of creating a field of inquiry valued by those it is intended to serve. (Barton, 2005, p. 318)

The issue of credibility *excess* or *deficit* seems highly pertinent to issues of emancipatory intent in addressing a testimonial justice. Fricker calls us to consider the importance of voice, not merely as levels of power, but whether their imagined social construction is active or passive (2007); because stereotypes have an impact on who is deemed worthy of knowing, it is as such 'a kind of injustice in which someone is wronged specifically in her capacity as a knower' (Fricker, 2007, loc 295). And while the active power in the relationship can be negotiated, the passive power exerted by the social imaginary may be less easy to ascertain. However, with little evidence of absence, other voices tell the story, and authority in them is achieved by trust in the storyteller. Moreover, epistemic justice cannot emerge from a single opportunity to speak, as handing over the mike mid-debate does not constitute a democratic dialogue. As Black women and women of colour have

fought hard to be considered equal both to white women and black men, disabled people need first to be recognised as having an authoritative voice amid a broad and diverse range of world debates. As Bourke and Phillips state, disabled people's enfranchisement is set against the enormous advantage and the struggle for equality, having to prove one's humanity (speech, consciousness and intelligence) on unequal grounds and against an unrecognised privilege leaves the fight unfairly weighted (Bourke, 2011; Phillips, 2015). A personal understanding of disability politics, activism and theory does place an analysis in a particular light. Goodley views disability research within the context of studies as:

... a paradigm shift; from disability as personal predicament to disability as social pathology. If we locate disability in the person, then we maintain a disabling status quo. In contrast, by viewing disability as a cultural and political phenomenon, we ask serious questions about the social world. (Goodley, 2012, loc 93)

Viewed thus, the theory in disability studies goes beyond matters of identity, speaking with an activism that equates to that of feminist, critical race or crip theorists. The discipline of disability studies with its underlying theory is the closest articulation of a disabled people's equivalent to critical race or gender studies. With the Social Model its shorthand for the need to address dis/ableism in the socio-political environment (Goodley, 2014; Brown & Leigh, 2018). As critical theorists, disabled researchers and activists, thus straddle many domains in their influence.

2.5.2 Working wisdom: sensitivity and conscientiousness

Working wisdom was chosen to describe the heart work (Hochschild, 2012) that is often added to skills in the paid role of workers. It is a nod to 'practical wisdom', the words used by Swartz (2010) in his TED talk, which articulate the ability to be empathetic and strategic at work. Here working wisdom is used to characterise subjectivity, in terms of technical skill or expertise, and the awareness of workers to the narratives beyond their organisation. The language of working wisdom is one of expertise, with tacit knowledge and positioning a matter to interpretation. It is not solely a

working narrative, but one that reflects a group telling in a language of values and morals (West-Burnham, 1988). As Swartz (2010) highlights, working wisdom has a characteristic language that conveys the intent to do the right thing, not simply the expected or the profitable, but to take action with other peoples' interests at heart. Empathy thus links working wisdom to other people's rights because it speaks to the required need to listen to the voices marginalised groups (Freire, 1970; Schön, 1983, 1991; de Waal, 2009).

Wisdom grows within dialogues that adds diverse perspectives, and more specifically help the building of knowledge with other people's views, with a moral intent secured by a 'dialogue with the oppressed' (Freire, 1970, p. 50). Gladwell describes practitioner wisdom as having a depth of shared knowledge, an extensive vocabulary on which to draw. By developing expert knowledge, 'our tastes grow more esoteric and complex... [we are] able to act intelligently and instinctively in the moment ... possible only after a long and rigorous of education and experience' (Gladwell, 2008, p.53). Storytelling is therefore critical, because conversation helps secured shared understanding: as a verbal journey in creating new possibilities (Senge, 2006). Conversations are the best ways of creating commitment, they are 'better than laws, because laws cannot change mentalities, and conversations can' (Zeldin, 1998, p. 28). Through many conversations with many disabled people and their organisations, I built a deep knowledge base built on shared stories.

Conscietizaco

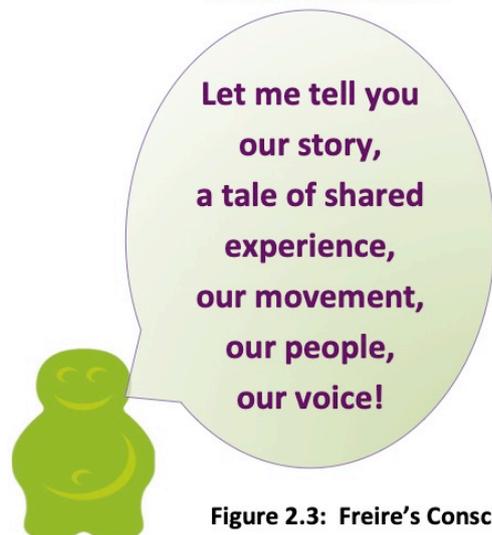


Figure 2.3: Freire's Conscietizaco

Critical consciousness, or Conscietizaco as coined by Freire (1970), puts a word to the awareness of a characteristic oppression – say ableism, sexism, racism etc. Critical consciousness can be empowering for the individual telling their story, as there is emancipatory value in knowing about structural discrimination and societal injustice.

However ownership of this experience – who makes the knowledge – is important. Narration has often been equated to authoring, yet as it is from a feminist perspective, men writing about women's interests has been seen as appropriation - taking power from a narrative of which they are not the authors, but *false* tellers in a paternalistic takeover (Mauthner, Birch, Jessop, & Miller, 2002).

In the storytelling about the disabled population, all that is authored is not owned, and much of what is owned is not told. In Freirian terms, storytelling is critical to empowerment 'unless one intends to carry out the transformation for the oppressed rather than with them' (1970, p. 49). Viewed as a group's conversation, legitimacy is not gained from one individual's isolated leap, but from a more staggered movement of many feet. From a group perspective, a democratic shift is rarely straightforward but often elliptical – a few steps forward, and then some back. More often it is a subtle shift with occasional flurries; the tale told is static but the storytelling is participative, involving dialogue and shared experience.

Being a disabled person no doubt influenced my interest in the research topic, but working wisdom offered a route to understanding theory in ways that includes politics, activism and civil rights.

Professional knowing is more than the ability to reflect on our action. In professional action, knowing is the action, involving competence to deal with the often messy, indeterminate zones of practice with their uniqueness, uncertainty, and value conflicts. Learning a practice entails initiation into the traditions of a community of practitioners and the practice world they inhabit (Kvale and Brinkmann, 2009, p. 93)

Viewed thus, working wisdom is the storytelling of a largely oral history from the world of business that acknowledges different disciplines and a diversity of individual experience (Shohamy, 2006; Schein, 2010).

Working wisdom colours interpretation, affecting the way a story is told. The articulation of disability studies is dry, with working narratives that often makes theory less accessible to workers. A thirty-year career as a disability equality practitioner gives a subtlety of wording for a nuanced storytelling in which the working world is examined from

Case sensitive

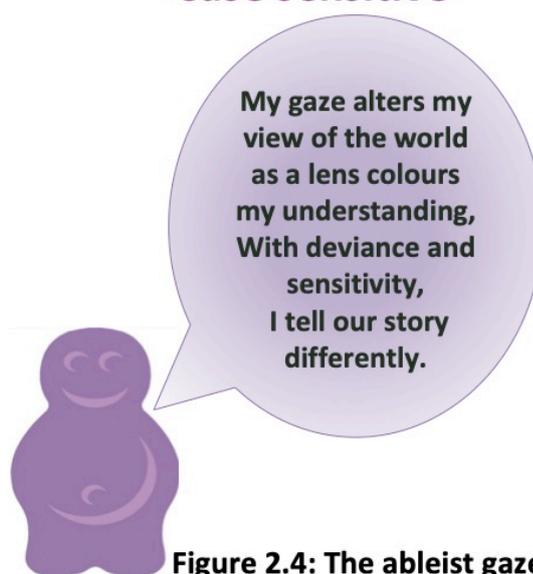


Figure 2.4: The ableist gaze

a theorist position. Sensibility and sensitivity have different meanings. The former refers to a heightened feeling or an over-reaction, while the latter is more akin to sharp awareness, a depth of appreciation, discernment and refined judgement. From an epistemological perspective, the important notion here is the character of the knowledge base, the working technical or skilled world-view, a coloured lens through which culture is represented – the *Kulturebrille* (Culture-Lenses) through which people see the world (Boaz, 1989; Monaghan, 2000).

Ruth Benedict's (1934) description of *deviance* is useful at this point. She uses it in relation to lesbian, gay and feminist agendas to describe the outsider's sensitivity within an insider culture. As



Figure 2.5: Research deviance

Benedict, a researcher can feel ‘attuned to the role of the deviant, the individual who does not fit into the dominant cultural pattern’ (Benedict, 1934, loc. 146). My questioning from an ableist standpoint does more to challenge practice, and my presence as a disabled woman is disruptive to dominant culture, it is deviant in its challenge to accepted cultural norms. In the words of Margaret Mead, again with reference to Ruth Benedict: ‘Because she asked the question about the relationship between cultures and abnormality... and of how the widening of cultural definitions might enrich

our culture and lighten the load of rejection under which the cultural deviant now labors’ (Benedict, 1934, loc. 148). Mead (2001), Butler (2006) and Benedict (1934) have referred to the role of deviant as one whose thinking does not fit the dominant culture pattern. Being an outsider brings with it a feeling of disconnection – for example when entering a place that is new to us. There is a word for this feeling in French: *dépaysement*. There is no exact English translation, but it means to feel unsteady or out of place, more literally, ‘out of country’. Ethnographic activity encourages the feeling of lack of belonging when an outside familiar surroundings, as it compares the process to travelling to a place where habits, customs and language are new to us. Being an outsider provides a perspective useful to culture analysis, enabling the researcher to notice the taken-for-granted – the assumptions that insiders no longer notice (Agar, 1994). What if the unusual actually becomes the sanctuary? The atypical organisation feels more comfortable, accepting and relaxed about difference.

“ I am not the deviant here. The organisation is. But, because I am ordinarily an outsider wherever I go. Here, in this place of unusual character I feel I fit in” [Fieldnotes]

So how do we define affirmative deviance? Or a culture that is more tolerant of the unusual, aware of additional requirements, open to mistakes and willing to be honest?

The sensitivity supported by working wisdom drawn from many decades of working conversations, that helped build the knowledge base which guides the interpretation. Not only a depth of understanding of the subject, but also a fluency and awareness of how workers react to it. Working wisdom facilitated an instinctive fine-slicing, akin to the auditor's response to a small anomaly in a spreadsheet, to avoid the bias and pitfalls of the inexperience (Gladwell, 2008). Madden explains the 'white male gaze' as 'one directed from the perspective of privilege; and as such in most circumstances it is typically a 'white male gaze' a way of seeing that combines gender and race as viewed from a 'dominant' position. Thus we might also refer to a 'feminist gaze', a counter-gaze that seeks to unpack and critique the 'white male gaze' (among other things)' (Madden, 2010, p. 97). An ableist gaze best describes my sensitivity as the writer, as a narrative is *always* prejudiced, therefore a definition of bias is important to the final storytelling (Benedict, 1934). The intentionality with which the worldview is articulated defines the unique perspective of a disabled academic with an equality and diversity knowledge base. The specialism of disability equality within Equality and Diversity is significant too, as ableism has a specific character, one that I can define fully.

The language of working wisdom is therefore in a very public sense one that articulates the understanding of a community of practice with a defined culture (Lave & Wenger, 1991). It is also a language used to narrate a shared story with an understanding of the complexity and nuances linked to the agenda of a group such as the disability movement. Working wisdom helps differentiate between having an impairment and being disabled, as stated here:

Having impairment is a prerequisite for being a disabled person but having an impairment cannot cause a person to become disabled... This new way of looking at disability turned received wisdom on its head and had a hugely liberating impact on many disabled individuals. It helped many activists, particularly in Britain, understand and challenge discrimination. (Slorach, 2015, loc 455)

In short it is my understanding of non-disabled people's privilege that holds validity here, not my increasing decrepitude. Sensitivity is important here, as a search for neutrality in line with a post-positivist world view is now rejected by many qualitative researchers (Agar, 1986; Silverman, 2006). The passion is in part motivation, as in the words of Archbishop Desmond Tutu, 'If you are neutral in situations of injustice, you have chosen the side of the oppressor. If an elephant has its foot on the tail of a mouse and you say you are neutral, the mouse will not appreciate your neutrality'.

2.5.3 Personal experience and proximity

I proudly call myself a researcher-storyteller because I believe the most useful knowledge about human behavior is based on people's lived experiences. (Brown, 2014, loc. 68)

Identifying a disabled, being an activist, or having an impairment is of critical relevance within the research design because who gathers data, analyses it and disseminates it is a power issue. Therefore all three are a consideration for ethics, particularly when research activity impacts on the private or intimate lives of any disabled people in a study. The emphasis questions the false dualism in research traditions that reflects a 'contrast between the objective world of physical things and the subjective world of 'meanings', between the public world of outer reality and the private world of inner thoughts, between quantitative methods based on a scientific model and the qualitative methods based on a kind of phenomenological exposure' (Pring, 2000, p. 33). As Andrew Wakefield's fraudulent research linking the MMR vaccine to autism sadly taught research networks, when workers who conflate and confuse terminology invade the privacy of individuals, experiments need to be deemed unethical and research discredited (Godlee, Smith, & Marcovitch, 2011). However, disabled people as researchers and defined solely as individuals with impairments, are no more likely to avoid the commodification of their participants' knowledge by virtue of their chosen identity (Stone & Priestley, 1996). All research needs to be responsible, accountable, fair and honest, in order to qualify as ethically sound. Personal experience is important, because it adds

a qualitative experience to research evidence and working wisdom. However, blended theory and inter-disciplinary sensitivity will impact on how experience is worded. Disabled people may have experiences that contribute to their understanding of theory or approach, but like any other researchers their textual contribution needs to come from a public position, not solely a private one, to qualify as activist. Personal experience does not come first, as ‘the same way that the original development of the social model resulted in a necessary correction to the overly individualized accounts of disability that prevailed in much of the interpretive accounts which then dominated medical sociology, so too has CDS [Critical Disability Studies] challenged the materialist line of disability studies’ (Vehmas & Watson, 2013, p. 639). Furthermore, proximity and familiarity with problems, issues or interest that touch disabled people directly make experience an important addition to a researcher’s knowledge.

Commenting on the way that feminist writers see the world through ‘gendered eyes’, Keith asserts that, “as a disabled woman, I too look at the world differently and there are issues and ideas, apparently invisible to others, which are very real to me.” (Morris, 2013, p. 1)

This point is reinforced by Beresford, who argues that interest and sensitivity diminishes with distance to personal experience: ‘The greater the distance between direct experience and its interpretation, then the more likely the resulting knowledge is to be inaccurate, unreliable and distorted’ (2003, p. 4). The same story can be told in a way that protects an individual’s privacy (while still highlighting what is critical to theory) by focusing on the language and the culture that impacts on all disabled people as a group in the act of public storytelling. Thus, framed as a shared experience, a personal voice is less likely to be dismissed by issues linked to the author’s perceived weaknesses or vulnerability. As Brown tells it: ‘vulnerability is based on mutuality and requires boundaries... it’s not indiscriminate disclosure... Vulnerability is about sharing our feelings and our experiences with people who’ve earned the right to hear them. Being vulnerable and open is mutual and an integral part of the trust-building process’ (2012, p. 45).

As this last section on evidence-based knowledge explains, the storytelling of research needs to mirror its an anti-ableism intent by being weighted to counter current imbalance with (a) the researcher as a respectful-activist taking on a public role with a specific aim to observe and question daily practice through a lens defined by sensitivity; with (b) the research evidence, working wisdom and personal experience positioned one below the other.

2.6 Ethnography - language and culture

As the chapter has highlighted so far, there is a need to take particular care when seeking, articulating and writing about disabled people's interests. Using ethnography answers a need to address the issue of privacy, because culture can often be viewed as data, with the analysis resting on 'the knowledge that people have learned as members of a group' (Spradley, 1979, loc 16). Public narratives hold the knowledge that defines the culture of an organisation and the language of its activity and purpose (Geertz, 1973; Agar, 1994; Schein, 2010). Language has been a linked to cultural theory, 'a theoretical construct invoked as a means of explaining the link between language use and social context' (Holtgraves, 2002, p. 38). In addition language has an emotional content in ways text does not, therefore words have the power to change reality by holding emotions such as a shared sense of possibility (Senge, 2006; Clarke, 2011). Ethnography also responds to a need to move away from the individualism in purely personal stories, because storytelling is a mediated relationship – a strong or weak connection - not a personal skill that confers status through ownership (Shohamy, 2006). Furthermore, as social action, language is a complex manifestation of human connection, a web of relationships expressed by art, music, accents, dialects, buildings and clothes (Shohamy, 2006; Ricento, 2006; Montgomery, 2008; Pennycock, 2010).

Placing the empirical site in context is critical, as the organisational culture can be viewed as a bubble against many, within the greater social narratives that perpetuate the stereotypes and assumptions imposed on the disabled population. These become the basis of unchallenged beliefs that are reproduced in storytelling the world over. This volume of words and text can be understood as dominance or power, as stronger voices will overshadow others (Shohamy, 2006), and the power of the oppressive or empowering nature of the bias within the story will build cumulatively from the position of the individual, outward to the group and across society (Thompson, 2007). The power of the grand narrative supports societal and structural ideas that reinforces cultural impact on internal dialogue that may become intensely harmful (Thompson, 2007). Seen this way, operating as power structures in the way the social world is constructed, some will become more accepted or believable than others (Thompson, 2007). When what really matters is talked about, meaning can be exquisitely precise, even when the actual words are intelligible (Shohamy, 2006).

According to Austin (1979) words and their meaning are influenced by society's stories as they hold heuristics, the myths, ideologies and beliefs that govern people's thoughts. This means that when engaged in conversation people can create insights that give them temporary glimpses into culture; and when observed indirectly culture 'is learned, revised, maintained, and defined in the context of people interacting... [it is] the knowledge that people have learned as members of a group' (Spradley, 1979, loc 16). With this in mind, dialogue is essential for co-production, because 'meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows' (Blumer, 1992, p. 2). While Wittgenstein described conversation as 'language games' – the speech acts that create recognised truths within our communities – Kvale & Brinkmann (2009) refer to these as an emerging story, a shared and dynamic reality, the story between tellers that creates a view of future. Sacks, by way of conversation analysis, give us the means of qualifying descriptions of performance (Silverman, 2006). Viewed thus, words are chosen

to reflect the audience, and are moderated by exchange, where power is negotiated (Simpson & Mayr, 2010). Social action then leads to a shared story, or fields of knowledge delineated by the language acts within them. Thus, language can be seen as the medium connecting people to place in ways that are 'creative, fluid, dynamic, energetic, changing, fluctuating and varied in terms of functions, places, contexts, personality, age, gender, groups, cultures, history and individuality' (Shohamy, 2006, p.7).

As Bernstein suggests, in conversation, words can be used as a shortcut to bigger ideas, complex theory, avoiding myths and contradictions in ideology (Moore, 2012). Therefore, the importance of how terminology references the disabled people's movement via disability studies is critical to keeping the authors as authors of overall storytelling. For example, by using the word 'disabled' instead of 'people with disabilities', the accent is in the societal oppression not the personal deficit. In the UK, the disabled people's movement has chosen the self-referencing term, to articulate the specific characteristics of the discrimination they face. Globally, however the advocacy movement seems to prefer 'people with disabilities' to suggest a 'person first' language. In Language Policy, this tension between activist and advocate groups is understood as a power struggle (Spolsky, 2004). Where words imposed by one group can have a different meaning to those silenced by it.

The storytelling in chapter six, 'Bathing the room in sunshine', is the re-presentation of culture through text. The chapter is a storytelling of the culture/language knot, it articulates accountability in its use of 'conjecture, inference, and a great deal of faith' (van Maanen, 1998, loc 360). New realities are created via the written word that can be interpreted through new narratives, with language as their tool of construction (Spradley, 1979). The ethnographic text, guided by its discipline, is used to get an account of the story told by the organisation. Set against a backdrop of orthotoxic society, the vignettes offer glimpses that specifically reveal the otherwise more woolly

elements that articulate legitimacy within the organisational setting - the doings of life (Madden, 2010). Text highlights what matters by describing the familiarity within the specific context in everyday conversation, thus respecting the collective space in which shared knowledge is gathered (Poole & Morrison, 2003). In the vignettes, meaning emerges that is usually deeply embedded in the banal, and often passes hidden in layers of tacit knowledge (Schein, 2010).

The task for ethnographers is to tell the explanatory stories in such a way as to find a middle road between the inductive and the deductive, between the particular, bottom-up theory and general, top-down theory. This process is called recursive or grounded analysis, and is undertaken in order to find an explanatory framework between the particular and the general. (Madden, 2010, p. 18)

Where the workers of an organisation have a direct impact on people's lives, the way they voice this relationship has relevance because in the short term an ability to tell the story of 'clients', stakeholders and partners holds power. The account held within the group will have an impact on those within the organisation, the stakeholders and their community beyond. While a story may be seen as static – a snapshot frozen in time – storytelling is a dialogue, an exchange with the possibility of a new reality where cards are reshuffled with each telling, creating new possibilities (Zeldin, 1998).

2.7 Ethical considerations: Being a care-full Feminist

This section reprises the points made about knowledge creation, in relation to the constraints of working with disabled people, and explains why an exploration of culture was more respectful and useful. Following University of Birmingham Business School Ethical review procedure, the proposal was submitted to the Humanities & Social Sciences Ethical Review Committee with the research methodology and received full approval to contact workers directly with consent forms and information notes. Anonymity was critical, so names have been changed, and gender hidden by using ‘they’ when appropriate. There are certain aspects of ReShape I have not revealed because these would make it too easily recognisable within its sector. Photos taken from social media are used purposefully to relay personal experience used in a public way source. Where fieldnotes were too revealing I have paraphrased them in order to keep anonymity. The empowerment value is maintained by the choice of methods, which aim to promote the most positive outcomes and *should* lead to better access to the support or resources for the disabled population as a marginalised group (Harflett, Turner and Bown, 2015).

The analysis of organisational culture allowed a look into the lives of people with significant impairment without eroding any private or intimate boundaries. I chose to focus on representation and not identity, in order to avoid any voyeuristic intrusion on people already subjected to the scrutiny of strangers (Silverman, 2006). As identified in section 2.1 and 4.3.5, the breaking of personal boundaries can be understood as harmful, because it is led by beliefs that are entrenched in the stereotypes characteristic of ableism. From an ethical perspective the investigation respects, or cares for, its people (such as an ethnography and action research) includes considering insiders first, safeguarding their rights and interests, communicating the research aims, and neither exploiting or exposing their privacy (Spradley, 1979; Madden, 2010). As Madden stresses, participants’ rights come first, with attention in any group thought to be disadvantaged, and ‘to invoke a hierarchy of

responsibility that has the participants at the top, ethnographer second, and the discipline itself third' (Madden, 2010, p. 90).

My intention was to observe practice, collect ideas, and engage in dialogue about the present and possible futures. The kitchen was a non-threatening place in which to ask questions, and a more naturalistic way of stepping into a typical exchange that was more public than private. I did not wish to disturb what can be sensitive work – or become *too* great a nuisance. The narratives gained from interviews drew on each workers authority in order to support the ethical nature of the research (Mauthner, Birch, Jessop, & Miller, 2002), and avoid the issues discussed above linked to non-emancipatory research (Oliver, 1997; Barnes, 2010, Harflett, Turner and Bown 2015).

In the ethical issues relevant to disabled people, and those with learning difficulties more specifically, three themes have been identified: 'freedom from coercion', 'disclosure of information' and 'competence' (Goldsmith & Skirton, 2015). There is paradox in 'learning disability' research regarding the protection of individuals against the need to include people with learning difficulties in order to gather the best possible evidence. Therefore, a focus on wider inclusion will result in a more robust body of knowledge concerning the health and welfare of people with learning disabilities (Goldsmith & Skirton, 2015). It was a central principle to promote the wellbeing of those participating in, involved in or affected by the research process, and to respect the dignity, autonomy, equality and diversity of all those involved in it (Warwick-Booth, Woodall, Raine, & South, 2010). This might be seen as an ethical burden for the researcher, but in the choice of methods, and in keeping with research approaches discussed in section 2.5.1, the developments in disability studies and their emancipatory principles. Respecting group interests aligns with feminist tradition, the ethics of care involving mutuality: 'real situations that are not abstract, the narrative describes actions or activity, but also aims to demonstrate respect: the

exchange of empathy, a reflexive action’’ (Mauthner, Birch, Jessop, & Miller, 2002, p. 27). As section 2.5.2 explains, defining working wisdom is not about striving for neutrality, but being explicit about subjectivity by acknowledging authorship – not penship.

As a tool, the researcher cannot be emotionally divorced from their own being: their internal mindscape is as important to their interpretation as the landscape they survey. A degree of passion is essential, as highlighted previously with regard to sustainability issues, for it fuels the desire to see injustice tackled (Patten, 2015). Empirical research – a process of interactive observation and reflection – allows ideas to emerge from the realities of the workplace (Blythin, Rouncefield, & Hughes, 1997). It is the analysis of these cycles that will then, in nuanced ways, inform the academics, workers and policy writers on matters of in/justice, as they are led by ‘empirical understanding and theoretically informed explanation’ (Dey, 2002, p. 106). The narratives of injustice that are identified in chapter four go to more depth on these salient matters about the lack of authority held by disabled people, despite their evidence-based knowledge, in interdisciplinary conversations.

2.8 Applying methodological assumptions to the research aims

An iterative loop of interpretation and representation was chosen, because a succession of principled steps was judged to support an emancipatory direction (later explored as dialogic action Sennet, 2003). Unlike more structured procedures, the use of an iterative process suited the fluid and unpredictable nature of the ideas emerging naturally from daily dialogue (Orton, 1997). A more technical approach could have been a barrier to the reflective thoughts that arose from unscheduled conversation – the often tentative sharing of tacitly held ideas (Madden, 2010). It was critical that the research process was executed such that power could be shared and the final account would represent a co-production of knowledge that was as equitable as possible (Cahn, 2000). This reflects a philosophical position that knowledge is socially constructed within the relationships of a group within a space (Spradley, 1979). An ethnographic methodology allowed for meetings that involve the power differences and conversations that unsettle and disrupt (Mead, cited in Benedict, 1934), which answers the call for a question of legitimacy regarding true knowledge, and what needs to count as useful in terms of value and answering ethical questions (Kvale and Brinkmann, 2009).

Initially it was difficult to stand back and avoid controlling events, or others, in a hypothesis-testing manner (Glaser and Strauss, 1967). Successive intervention stages enabled improvisation, and in the style of the values of research, held the robustness of process while ‘neither the theory nor the data is fixed’ (Orton, 1997, p. 432; Townsend A. , 2013). Although the text can be viewed as an auto-ethnography, it is not, the methods were chosen to give a collaborative story: ‘a multivocal approach in which [many] work together to share personal stories and interpret the pooled autoethnographic data’ (Lapadat, 2017). This recursive checking added to the final storytelling and helped empower workers, which was important as those who might identify as disabled people needed to contribute without a need for disclosure. This idea of a public conversation fits well with

the social activism aspect of co-constructed texts, as it creates opportunities to ask conceptual questions, with the answers showing how workers organise their knowledge and how within a community of practice they are able to share (Flick, 2009).

2.9 Stepping forward

This chapter has introduced a number of constraints linked to research about disabled people, particularly those with complex impairments. It has outlined the void that in the past has characterised forms of ontological silencing levelled at the disabled population: an epistemic injustice perpetuated in the storytelling of research. This absence of balance and order within types of knowledge, which then gain an assumed custom, define the ableism, not disablism, that *others* disabled people as lacking authority as authors, writers and knowers. Despite their growing academic contribution to a wide range of fields, this means they are often ignored. It is within this research landscape, typified by a lack of trust in disabled people's contribution, that their interests as a group are largely muted, so that without an academic voice, their experience is further discredited by its individuality within narratives that are influenced by the individualism of society. A re-articulation of evidence-based knowledge was therefore proposed to adjust the weight of research evidence and working wisdom in order to address ethical concerns in this research. Weighted this way and used in analysis, the gaze will help expose the injustice, ambiguities and complexities found in the textual storytelling of human rights literature. Personal experience of disability, is not ignored, but retuned in order to stress and validate the experience of ableism in first-hand accounts, hence the importance of testimony in an articulation of proximity to discrimination and harm. The aim is not to refute past knowledge, but add an explanation of the ableism often levelled at *non-disabled* researchers possibly unaware of the power dynamics in society more widely. The ethnographic philosophy also aimed to support a knowledge co-constructed with a working community – as 20% can be expected to be disabled - makes it more

socially just. The next chapter outlines the methods used to secure this approach to evidence-based knowledge in this research. The advantages of multiple data methods are outlined in plotting the path that emerged from *being* in the field.

Interlude

Hard to hear!

Face to face conversation is fraught with ethical considerations. People's privacy needs respecting, and their position in society needs to be dealt with sensitively. While a first-hand exchange seems straightforward, words are not data to be dealt with dispassionately. A full and wholehearted exchange is only possible if time, cost and energy are not available to pay for the things that will help achieve a shared tale. There are many reasons why the more powerful pens telling of lives in research have spread much ink yet silenced disabled people's voices.

Traditionally non-disabled researchers have had control over Jean's story. They had power, as writers, to use their privilege in a world where people like Jean are seldom seen and often ignored. The difference between author and narrator is huge, the pen gives power to tellers with the ink. The further Jean's words travel, the more likely they are to be twisted, sometimes forgotten, and often changed. When a sensitive narrator steps close to her, because they have power they are likely to influence her, her meaning is changed if not her words. She's likely to want to please, trusting a writer and therefore allowing her privacy to be invaded, leaving her exposed and easily hurt. All too often accounts re-present the stereotypes of triumph-over-tragedy, personal deficit and inhumanity. Words that establish the tropes that make us believe in Jean's failure, not society's inhumanity.

To address these matters, the investigation was not about a life that is unique, or the truth in a testimony, but about asking what refutes it, shapes or moulds it. What does society's storytelling say about disabled people, and why is their truth not heard across neighbourhoods or around the world? The way culture shapes language helps us see how the media's tales can create a hostile landscape littered with myths.

Believing, with Max Weber, that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning. (Geertz, 1973, p. 8)

Chapter Three

Webs of Culture

3.1 Methods

In the last chapter ableism was defined as an articulation of the misrepresentation of disabled people in text, and characterised by an unacknowledged lack of trust in the voice of disabled people whose absence is identifiable across a number of textural worlds. More importantly, disabled people's authority was outlined to rectify a bias in which the research evidence, working wisdom and personal experience of disability studies is skewed within other disciplines by poorly articulated narratives. A specific weighting of evidence-based knowledge was proposed to address this particular domestication of disabled people voices in academic writings. In section 2.4, a more nuanced terminology was offered, because there is a lack of words to describe disabled people's interests, and to articulate the complexity of systemic and societal oppression, in a legitimising dialogue to achieve accountability. Evidence-based knowledge was then applied to the ethical considerations of this research to help avoid any re-production of the characteristic testimonial injustice levelled at disabled people that denies their authority as co-producers of academic contribution in interdisciplinary narratives.

In this chapter, chosen methods are outlined to explain how text was used to represent language and culture (Agar, 1994). Because ethnography is recognised to have intrinsic political and ethical value, it suits an exploration of phenomena sited beyond the individual by helping to represent the storytelling within organisations (Davis, 2010). This textual evidence aimed to generate the rich data on which practice was reflected on to inform theory (Dey, 2002).

The web in the title refers to how methods relate to each other in an interwoven manner, rather than a hierarchical one. As Helgesen (2005) describes, a web is a more inclusive map than a tree or chart whose representation imposes a tiered status. Culture is as slippery an eel to analyse, so methods from anthropology and sociology are used to help tie 'together—fieldwork and culture—as well as

the knot itself' (van Maanen, 1998, loc 765). Language is the action used to connect meaning, the words that articulate human relationships, and the weaves of narratives between people and within a place. As Geertz puts it: culture is the 'ordered clusters of significance ... [and] man is an animal suspended in webs of significances he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law' (Geertz, 1973, p. 5). Viewed thus, as listed below, different techniques are used to draw meaning from complexity, 'an interpretive [view] of meaning... construing social expressions on their surface enigmatical' (Geertz, 1973, p. 5). The methods respect the collective space in which shared knowledge is gathered (Poole & Morrison, 2003), as I wanted to show that the exceptional is deeply embedded in the mundane and banal, hiding knowledge that often remains hidden in layers of tacit culture (Schein, 2010). Culturally significant events give 'public expression to the ideational system' (Dent, 1991, p. 707), which is produced and reproduced through the telling - and retelling - of stories, not just lodged in people's minds but in a public space.

Telling a group's story can be seen as disrupting existing assumptions, highlighting what is ignored, and challenging a status quo that perpetuates injustice (Kafer, 2013). The rigour and veracity of authors are established with the ethnographic account flowing 'from the concepts and meanings native to that scene rather than the concepts developed by the ethnographer' (Spradley, 1979, loc 33). Dealing with interpretation, the validity of the naturalist researcher's task is not to provide transferability but a rich description, so that readers may learn and contextualise according to their own circumstances (Lincoln and Guba 1985) hence the use of transcribing observation into texts that are then analysed to highlight interest and tell a shared story (Spradley, 1979; Kvale & Brinkmann, 2009). These next sections describe the techniques employed to achieve this written evidence, because 'culture is not itself visible, but is made visible only through its representation' (van Maanen, 1998, loc 360).

3.2 Aligning methods with social justice

It is not the tools but the theoretical and philosophical grounding that determines whether a method can be labelled socially just. The iterative-interpretive approach can sit within an emancipatory methodology, because the tools and character of the analysis are guided by an anti-ableist intent (Mladenov, 2016). This leads to a product – an account - grounded in principled action and the values of social justice (Minkler, 2012). The processes of iterative research, often referred to as a ‘recursive or grounded analysis, [are] undertaken in order to find an explanatory framework between the particular and the general’ (Madden, 2010, p. 18). The methods are varied but not random, as they all sit within the assumption that knowledge is co-constructed (Madden, 2010). The text, more specifically in Chapter 6 ‘is used to generate a narrative-based interpretation of the events that took place’ (Dey, 2002, p. 106). For this reason, although I write the narrative in the first person, the journalistic style is used to describe a third person in the performance (Spradley, 1979). The methods used supported fluidity, and created opportunities to ask conceptual questions, which explored the way language was used within an organisation (Flick, 2009).

I chose team meetings, organisation events, interviews and observations, because they enabled me to write the story from within the action. The proximity gave me an ‘understanding of the language, concepts, categories, practices, rules, beliefs, and so forth, used by members of the written-about group. These are the stuff of culture’ (van Maanen, 1998, loc 465). I knew I would be involved in the lives of disabled people, as workers were likely to have impairments, but I was keen not to single out disabled individuals directly as objects of study, as others have done previously (Oliver, 1997). Inference from second-hand data is adequate to provide the evidence-based knowledge that characterises the narratives of injustice required of research aim 2. As Silverman explains with regard to sexuality, we ‘often falsely assume that there is inherent difficulty in obtaining naturally occurring data because of the supposedly private character of many settings, e.g. family life or

sexuality... family life is going on all around us – in courtrooms and social security offices as well as households... sexuality is hardly confined to the bedroom; discourses of sexuality are all around us too’ (Silverman, 2006, loc 360). Therefore, I used narratives that refer to ableism, directly or indirectly, to explore cultural references to the ableism disabled people face, as these are in the public domain and therefore somewhat removed from individuals’ private lives (Chapman, 2011). Costs soar when creating participatory research with people entitled to accommodation, and specific consideration is needed to uphold rights to ‘freedom from coercion’, ‘disclosure of information’ and ‘competence’ (Goldsmith & Skirton, 2015). As a PhD effort, neither the finance, the time or the personal capacity was available to make this research fully participatory in the sense of achieving emancipation for any one disabled individual (Cook & Inglis, 2012).

3.3 ReShape, its place & its people

As explained briefly in section 1.6, the reason for choosing ReShape as an empirical site of specific interest, was because in working exclusively with disabled clients its daily activity, language and culture is characteristic. A review of sustainability literature suggests little research activity within SMEs as empirical sites, and paucity in the area of human experience because most methods use documentation rather than on-site involvement (Thomson, 2007; Thomson, 2014). Probably because working at close quarters with people gets messy, and you need to muck around with data and relationships (Cha, 1986). The research took four years, during which I had planned to spend four weeks at ReShape in periods of 4-5 days over a period of 18 months. I had scheduled the visits every six weeks in order to be available and present on site for existing meetings. This did not always happen as planned: I underestimated the exhausting nature of the work, and needed more time to write between visits. However, over the period of 18 months I made 12 shorter visits, in addition to the time spent working with the organisation before the study, which certainly proved more than sufficient to generate large quantities of field notes. The issue of access can be a delicate

one, and asking to be included in workers' lives comes with positives and negatives in terms of honesty, accuracy and trustworthiness. However, being care-full allowed boundaries to be respected; for example, I was hugely aware of decisions I made around public and private information. However, being known was enormously helpful. A disabled person entering a new relationship is fraught with issues such as prejudice, fear, and opportunities for others to hurt or harm. Therefore, to secure a *fairly* undisturbed environment, and for my own comfort and safety, being known made sense to investigate matters within an organisation in which I felt safe.

In line with the ethical considerations of not wishing to cross the privacy boundaries of the disabled I spoke with, and the costs of truly participative research, the site offered instead an alternative narrative that contrasts significantly with the way disabled people are perceived more commonly in society. By offering an alternative to institutionalised living, a service wholly built around disabled individuals' choice, ReShape brakes its sector's rules. Thus, the organisation offers an insight into disabled people's interests, as it is uniquely led by the disabled individuals it serves. As Spradley (1979) states you do not have to be in someone's bedroom to talk about sex, it can be discussed in relation to its representation. In a similar way, ReShape offers a representation that differs from the norm, a rare view of a culture where disabled people are known and draw little ableist bias.

Its geographic site is interesting too, as the organisation sits within a locality where human rights conversations are frequent. Scotland is recognised as having a culture where 'making sure those who are experiencing human rights issues have their voices heard in decision-making' (Scottish Human Rights Commission, 2018, p. 6). Trust also emerges as the factor that, under the overarching themes of 'freedom of speech' (17%), 'equality' (15%), 'rights' (11%) and 'fairness' (10%), helped people talk about human rights in ways that help to underpin their campaigning and

advocacy efforts in policy, in which the principles of emancipation, accountability and equality were integral (Scottish Human Rights Commission, 2018).

3.4 In the field

They are to do with wild herds of sentences, out on the open range. (Agar, 1994, p 16)

The following four sections outline different methods used to capture conversations *on the range*. These helped weave a map of the different narratives beyond ReShape, so I could compare and contrast this with those taking place within its walls.

3.4.1 The worldwide web: cyber-ethnography and social media

With much of life now happening online, the question of voice cannot be considered fully without some attention to the worldwide web. I find this somewhat ironic given availability of tech and its coverage globally, as a way of communicating in a public space without passing a paid gatekeeper (Kozinets, 2015; Carty & Reynoso Barron, 2019). From groups, to blogs, to social media, the conversations we have nowadays rarely go without reference to Facebook, Twitter or Instagram. In relation to storytelling more specifically, the web can help reconceptualise storytelling ‘as a setting for responsibly reconstructing, representing and recounting entangled individual stories’ (Kozinets, 2015, loc 366). Cyberspace is becoming increasingly populated by those keen to be acknowledged as disabled, with the blue-chair emoji for example, now common on many Twitter handles. As the events in Egypt in 2016 suggested, ‘the increasing importance of web-based platforms that allow people to construct a public profile, connect with others and thereby participate in society... It is a way to organize disability rights actions, let others know about disability related news, promote events, or just find like-minded disability rights advocates (Ellis & Kent, 2016, loc 380-386). The medium is interesting, as it has offered choice to those wishing not to declare their impairment, and while activism has become more noticeable, engaging online has become cheaper and more

accessible. Cohen states that cultures and ‘communities are ‘worlds of meaning’ that exist purely because of their continued adoption and use ‘in the minds of their members’ (Cohen, 1985, p.82) with people in ‘all their multiplicity, heterogeneity and unpredictability, come before cultures and communities, ontologically and morally’ (Kozinets, 2015, loc. 343).

Cyber-ethnography (Hine, 2015), or ‘netnography’ (Kozinets, 2015), has increasingly become a research method for obtaining meaning from the web by gathering voices from online feeds.

Netnography is, instead, specific sets of research positions and accompanying practices embedded in historical trajectories, webs of theoretical constructs, and networks of scholarship and citation; it is a particular performance of cultural research followed by specific kinds of representation of understanding. (Kozinets, 2015, loc. 180)

I chose the use of social media more specifically because it allowed public access to, observation of and participation in global networks and groups that exist only online. Each has their own language, apparent in recognisable terminology, some activists, others workers, allies and families, all with cultures of their own. Yet again, I used judgement in my choice of groups, organisations, individuals and texts. For example, early on I closely followed the Disability News Service website (Pring, 2013). However, it soon became apparent that other leading disability activists, and those academics from learning difficulties studies more specifically, critiqued this website for its lack of evidence-based assertions. While I did not dismiss what I considered an important voice for many disabled individuals, I was more measured in the way I added their view to this research.

The web has become an increasingly nuanced tool for researchers. From online chat groups to open broadcast tools, the medium of self-expression in on the web is expanding rapidly. Both Facebook and Twitter provide a place for online community activity but I chose them for very different reasons. Facebook is more akin to a sitting room or classroom: the space is private, relationships are typically close and content can only be exchanged between known parties. The drawback therefore

is the ‘echo chamber’ effect, only one part of any conversation can be accessed easily. Twitter, by contrast, is more like a conversation in park or coffee shop, tweets are public and far more likely to be seen by many. A particular favourite platform was the now-deleted Storify, which collected posts and tweets by theme, hashtag or handle. This technique allowed me to capture the highlights of conferences, which could then be shared or sampled for insertion in other text. For example, the screen-grab below was taken from the Story website which helped curate the hashtag #ableismconf from a Critical Studies of Ableism conference at Manchester University on the 19th June 2017:



Figure 3.1 Ableism Conference Tweet

Constraints are overarching, however the worldwide web still provided a method of gathering language and the culture of groups sharing a common interest, and I was able to gather quite lengthy timelines highlighting topics, narratives, literature, online resources and personal thoughts. In fact, the added passion with which some narratives unfolded online provided much evidence of the passion often lacking in academic debates.

Affection, love, disappointment, anger, intrigue, repulsion, belonging and culture shock are all experienced as real by participants in cyber societies. Such real experience utterly problematises the value judgments that flow from a view of ‘real’ society as authentic, and ‘virtual’ society as fake. There is nothing fake about the reality of online sociality. (Madden, 2010, p. 179)

Twitter provided great insights into the terminology used to create meaning of disability and the understanding of how this is shared. Politically, for example, during the May 2017 election, the hashtag #theCripVote trended, with many disabled people expressing their distaste for politicians and parties regarding welfare and benefit reform. Ian Duncan-Smith's resignation also registered loudly, with mirth and venom spewing in equal measure. As the literature review will explore, a conversation about the human rights of disabled people is taking place outside the *walls of institutions* and in real time. Having considered and dismissed oral histories earlier in the research, I found cyber/netnography far more useful to exploring the group/society interaction. Social media felt more relational, fitting with the evidence-based knowledge and social justice angles, as it is both democratic and levelling in terms of voice.

3.5.2 Observation – hearing silences and nonverbal communication

The observation stage of the research action can be compared to action research in the sense that it was planned with a principled approach but followed 'participant' activity (Townsend, 2015). I knew it would be hard to find the voice of individuals in any other way than to sit beside them and watch (Cook & Inglis, 2012).

Participant observation is a whole-of-body experience that has us observing with our eyes as we participate, but we also 'observe' with all our senses... Good ethnographers while use their whole body as an organic recording device. (Madden, 2010, p.1)

The way we talk in different contexts not only needs different vocabularies but also different tones, tempos and inflections, so that moving between conversations is fraught with complexity, uncertainty and hesitation (Shohamy, 2006). I felt that incidental observations became as important as planned meetings. It was the nonverbal communication that became far more central to the piece than I had anticipated as an outsider (Lovett, 1996). I have been aware of elective mutism, non-verbal individuals and supported communication for over a decade. These are contentious issues in matters of equality and inclusion, and the subject invariably arises on equality training courses. I

have therefore used both sensitivity and a fluency in the recognition of nonverbal language as behaviour in communication within storytelling and furthers accounts (Lovett, 1996). I was keen to tune in to nonverbal cues and to explore the emotional resonance of silences in this context, especially given the significance of disabled people, which includes those with significant impairments, in this study.

3.5.3 Facilitated groups

Through persistent lurking I was invited into conversations about salient aspects of organisational life. As a participant in conversation, I used group conversation to gain insight into aspects of shared knowledge; my interpretation was neither subjective nor objective because the role is interpretive: ‘mediating two worlds through a third’ (Agar, 1986). Making knowledge tacit through writing, the texts would I wrote illuminated a storytelling that often goes unsaid (Spradley, 1979). I deliberately asked difficult and absurd questions in order to bring accepted ideas out into the open. In this way, in-depth dialogue also offered ways of validating the experience and wisdom of those with whom I spoke (Kline 1999). Less formal than interviews, conversation helps to empower workers and volunteers, which fits well with the social activism aspect of co-construction, and the overall theme of empowerment (Wheatley, 2002). From this perspective, group conversation helps create shared knowledge in the connection between participants (Kvale, 1996).

Facilitated conversation has long been a favourite ‘training’ technique in my toolkit. Here it allowed my exchange with workers to help shape new and emerging knowledge. I used scheduled meetings to ask workers about the key themes I identified, sometimes presenting aspects of these themes as they appeared to me. Group conversation was also useful to pose questions that were then considered between sessions. This enabled me to gain a detailed insight into what workers felt made a difference to the people the organisation served. When listening becomes a tool, it is an

intentional way ‘of paying respectful attention so that they (those interviewed) can *access their own ideas first*’ (Kline, 1999, p. 39). In this way group conversation becomes a way of acknowledging others’ experience within an environment of mutual respect, because listening demonstrates empathy (de Waal, 2009). We were all aware that interviews were not just a ‘chat’: they were planned to respect workers’ time and were therefore purposeful. I gave workers an overview of the study, answering any questions and clarifying intent. From my perspective, I used everyday language to probe into their practice and its impact on people they served. I also sought to demystify the work I was doing, in order to encourage sharing and joint building of ideas in accordance with Spradley (1879). As Seidman suggests, ‘interviewing is very often the best way to proceed if researchers are interested in the life experience of people and the meaning they take from those experiences’ (Seidman, 2013, p. 40).

3.5.4 Individual interviews

The less formal chats were complemented by nine semi-structured interviews with individuals. These were added to group facilitation sessions and involved conversations about practice as well as supported reflective thinking time with members of the management team. As a researcher I was mindful not to add to the accumulated pressure workers face: their time away from work needed to offer something more valuable than a cuppa. Interviews explored specific points previously identified in the more casual conversations. By spending an hour with each worker, I probed ideas that I had identified through general conversation, to gain a better understanding of key aspects of shared knowledge. I also used the interviews to clarify points I had noticed about ideas and language, giving me deeper insight into what had meaning for the workers within the organisation. For example, the interview with the financial manager revealed that the people the service supports are directly affected by the organisation’s financial arrangements, because amounts as small as £5 impacted on budget, therefore their control and wellbeing both key to enabling choice.

3.6 In the chair: textual worlds

‘the tale to be told on return home’ (Kvale, 1996, p. 4).

The task of textual analysis was far too nuanced for any computing technique, therefore the tool was my own judgement, and applying evidence-based knowledge to the analysis to gain an interpretation required a high degree of sensitivity (Pennycock, 2010). Looking for the voice of disabled people within texts relies on detecting indirect meaning from nonliteral wording, and understanding inference and emotional intent (Holtgraves, 2002). It was not words I looked for, but their use in far wider-reaching debates, such as independent living or human rights (Thomas, Wareing, Singh, Stillwell Peccei, & Jones, 1999). For example, it was the meaning of a ‘problem’ or the implied ‘interests’ of the group that I looked for, not the exact words used (Minkler, 2012). I used the online library to search for journal papers, and started the search on the database with the widest and most indiscriminate approach possible, by typing ‘disab*’ as disabled, disability and people with disabilities seem to be used interchangeably throughout online journals. The first iteration took in a 20-year period, which I narrowed to five years once I recognised the key words and phrases used to convey recurring themes. I then used these themes as indicators of a shared voice in the text. That is to say, I began to recognise the presence of disabled people’s interests beneath the text (even if the words did not express it clearly). I looked for a link between the use of certain language and theory, for example the articulation of the Social Model, and the use of ‘disabled’ in preference to ‘people with disabilities’.

With my analysis framework established, I searched for literature that articulated an understanding of disability studies, disability movement voice, or the interest of disabled people more loosely. I tried using disability with these other words, and changed my search to journal entries relating more specifically to accounting, human rights and accountability. The tools for analysis described below

are used as an interpretive method of building evidence-based knowledge. Together, language policy and disability equality helped me describe culture, in order to then articulate notions of accountability in words that conveyed ‘disabled peoples’ voices’ in debates of global concern. As I explained above, I opted not to talk to disabled individuals directly, not because their experience is not valid, but because in being a unique personal truth, it does little to answer a question about shared voice from an organisational or societal perspective. Exploring identity has numerous uses, but I wanted answers to what enhances or erodes the impact of a negative narrative. I wanted to find out how an organisation can change the story about disabled people. In terms of accountability, more specifically, what constitutes legitimacy to a population with a distinct character within the orthodox-toxic culture they face? What keeps the personal unique and the shared, authoritative?

3.6.1 Disability equality

While disability studies and disability equality differ, with the former expressing an academic view often written in the arcane language of the theorist, the later expresses a more accessible working wisdom in language intended for multidisciplinary audiences. Disability studies focuses largely on the critical ideas that help articulate ableism, not so much the bias or prejudice, but the institutional discrimination and societal oppression that fuel ableism (Kumari Campbell, 2009; Kumari Campbell, 2019; Goodley, 2014). Disability studies can be of use to critique the equality duty in law, for example, pointing to its compliance approach to accommodating as a minimum duty, without challenging the institutional rules and societal inequalities that entrench discrimination of this kind. As I have outlined earlier, who tells the story greatly influences trust in its authority (Fricker, 2007). Therefore, while disability equality secures a voice for disabled people, as more than the sum of individuals with impairments, in its storytelling it holds the interests of the disabled population and the political view of their movement. In its telling of culture, the product in Chapter 6, as is an interpretation of events from an activist’s perspective, because the ‘task for

ethnographers is to tell the explanatory stories in such a way as to find a middle road between the inductive and the deductive, between the particular, bottom-up theory and general, top-down theory' (Madden, 2010, p. 18).

Disability equality training, unlike disability awareness training, emerged from the campaigns of disabled people's fight for equal rights (Morris, 1995). The training extended the education of Equality and Diversity in social work of sexism, homophobia and racism, with a similar approach to teaching disablism. Most crucially it had to be *led by disabled people*, although 'there was initial resistance to the new group of disabled people (called the Disabled Trainers' Forum) working in the field' (Campbell & Gillespie-Sells, 1991, p. 4). Formalised in 1985 by the 'Disabled Trainers Forum' (Barnes, 1991, Section 2 – online text has no page), Disability Equality practitioners needed to have a personal experience of disablism, as this gave them a proximity to the very issues that underpinned the social model of disability as a tool (Oliver, 1990; Beresford, 2003). The distinction of disability equality, in addition to not being delivered by non-disabled workers, was that it was grounded in the thinking of the disabled people's movement. It states that disabled people are not the problem, but social and environmental barriers are, hence the medical and social models of disability. This helps avoid the specific characteristics of disability stereotypes – that disabled people were faulty and needy – and the assumptions linked to the disempowerment enforced (possibly unwittingly) by medical workers or clinical experts (Morris, 1995; Oliver, 2016).

The impairment is the focus, and the individual is viewed as faulty.

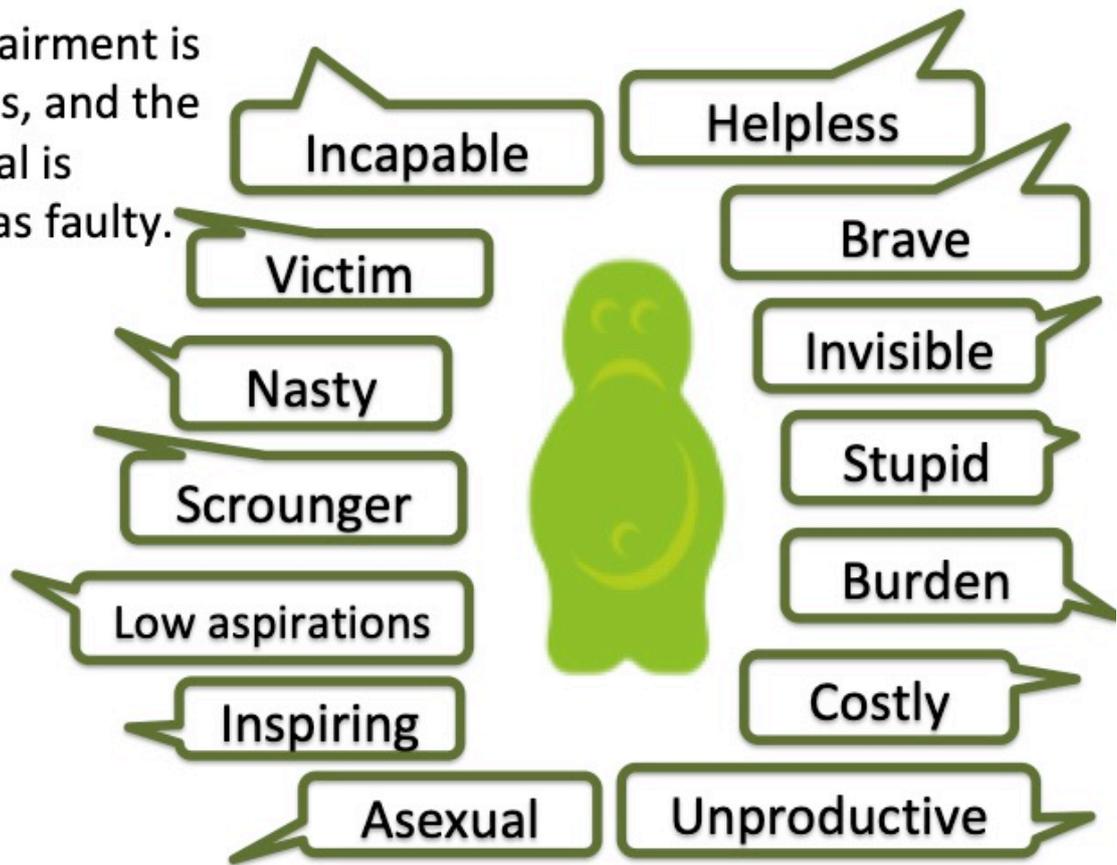


Fig 2.2: The medical model of disability

At a simplistic level, according to Oliver (1996), the medical model of disability as a tool helps in asking the question ‘What is wrong with you?’ and the social model of disability helps ask “What is wrong with society?’ This dichotomy fits the wider perspectives of this research that is informed by the research literature.

Medical model thinking is embedded within our culture – as deep-seated as sexism, and as damaging. In spite of the government, and many local authorities, claiming that they take a social model approach, eligibility for benefits and services is still determined by assessment of how much our bodies are affected by impairment and/or illness, rather than the disabling barriers we experience. (Morris, 2013)

As figure 1.3 shows, the medical model of disability articulates the stereotypes and beliefs about disabled people in mainstream storytelling. These can have an impact on disabled people, as stereotypes are a reaction to oppression, which is then seen as a story rather than a reaction -

internalised oppression (Chapman, 2011). The negative stereotypes (see figure 1.3) also create bias in the hearts of those writing papers, legislation and policies. As a societal narrative, more generally, stereotypes change the storytelling about people's lives, hiding in the orthotoxic culture that imposes dis/ableism on disabled people. As figure 1.4 depicts, dis/ableism can be understood as an environmental and societal issue that impacts on marginalised groups. The social model of disability views inequality as the interest that concerns everyone, in which disabled people's voices are a known quantity. Disabled people are visible, equal members of global networks, and local communities, and thus contribute in all areas of societal change.

Disabled people speak for themselves in a conversation about global issues.



Fig 3.3: The social model of disability

The direction and content of speech bubbles above expressing the contradictory character of oppressive ideas and the narratives of injustice explored in chapter four as a layering of successive toxic stories – taken together as culture and its language of ableism.

Disability equality has its roots in activism, but the theory and/or knowledge is more typically built through networks, stories passed from one disabled person to another. As I will explore in great detail in chapter two, the reliance on non-peer reviewed literature and storytelling is key to understanding the ontological, epistemic, and methodological issues of this research. Limitations and criticisms of disability equality training, include that little attention is given in passing on the story in training to other thinkers: models of disability are offered as truths, rarely criticised and hardly ever critiqued. The information delivered is informal, but powerful in its political strength, yet poses the question of whether the conception of disability as purely a product of social arrangements which theoretically can be reduced or eliminated is helpful and suggests it has ‘created as many problems as it has solved’. Furthermore, most people with an impairment are disadvantaged by their condition as well as disabling barrier in society (Shakespeare, 2013).

3.6.2 Language policy

Culture starts when you realize that you've got a problem with language, and the problem has to do with who you are. Culture happens in language, but the consciousness it inspires goes well beyond it. (Agar, 1994, p. 21)

As a tool, language policy provides a way of interpreting the power dynamics between and within group conversations. This is useful when looking at legitimacy beyond the organisation. Furthermore, culture changes when language becomes ‘the major tool for political and oppressive actions, for manipulating and controlling the social order of ... the lives of groups and individuals’ (Shohamy, 2006, p. 29). Thompson states that ‘a discourse is literally a conversation, but is used to refer to frameworks of language, meaning or behaviour that contain within certain ‘power rules’ (2007, p. 5). Hugman (cited in Thompson, 2007) argues that narratives viewed as a discourse is more than language: within institutions culture can be understood as a link between the power of groups and individuals. The public and personal creation of meaning through ‘language is personal, individual and unique, it is also social, dynamic and changing as common features are shared,

negotiated, and created by individuals as part of the need to maximize the quality of the communication and interaction' (Shohamy, 2006, p. 7).

In language policy terms, the culture of the organisation served to articulate a space that usually marginalised disabled people's storytelling (Holtgraves, 2002). As detailed above (in section 2.5), the methodological assumption is that knowledge can be co-constructed. There are therefore knowers and storytellers, which unfortunately allows for some knowers to be ignored or silenced as authorities despite their authority. To counter any epistemological injustice, therefore, the research action was used intentionally to articulate a contextual narrative – an interpretation - of a specific location exemplifying a distinct working community. I employed ethnography in the design in order to articulate a tacit culture. This provides a product in chapter six, which is followed in chapters seven and eight by an interpretive reflection on text and process. As the human research tool, I aimed to deliver an account – an interpretation of shared experience from a critical perspective. Judgement requires being, not just doing, and therefore includes emotion, involvement of the heart and the head in the context of the field and the actors (Sergiovanni, *Landscapes, mindscapes, and reflective practice in supervision*, 1985). As stated earlier, ReShape is a unique empirical site, and therefore provides a rare insight into a working culture in which disabled people are trusted as co-contributors. For this reason the place offers a rare disruption in the ableist assumptions found in orthotoxic representations in the world. The positive and longstanding relationship I had with workers allowed access and frequent interaction. More specifically, because of the disabled client group, the culture was defined by their positive, atypical and upbeat attitudes towards disability. Furthermore, because of the disability-friendly environment, typical triggers of prejudice and unconscious bias were rare (Pettigrew, 2006; Gladwell, 2008).

In this section I offer ethnographic tools as ways to explore language and culture, and ReShape as a place where language and text is used to express shared knowledge through word and artefact (Spolsky, 2004; Shohamy, 2006; Ricento, 2006). This view of meaning and ideas that are held within relational networks, where words can be used precisely or figuratively, refined and altered, with purpose to engage in nuanced ways of working, common values and joint purpose. Language can be seen as a flexible connection between people where ‘personal languages [are] creative, fluid, dynamic, energetic, changing, fluctuating and varied in terms of functions, places, contexts, personality, age, gender, groups, cultures, history and individuality’ (Shohamy, 2006, p.7). Fairclough (1989) argues that language carries significance in terms of power and authority, as he asserts that language use produces, maintains and changes power relationships, with language seen as a complex social manifestation of human connection, a web of relationships expressed by art, music, accents, dialects, buildings and clothes (Shohamy, 2006; Ricento, 2006; Montgomery, 2008; Pennycook, 2010). In recent years, language has been linked to cultural theory, ‘a theoretical construct invoked as a means of explaining the link between language use and social context’ (Holtgraves, 2002, p. 38). Alternatively called languaging (Shohamy, 2006), or languaculture (Agar, 1986), Language Policy theory allows distinction and contrast of the terminology used by a group within a place – its particular narrative or conversation. It is the organisational activity that provides the reason for terminology, a web of meaning or a bundle of words, the culture and the language that ties together what people do and the purpose it holds (Chapman, 2016). Culture, similarly to a community of practice which is currently used to denote groups where people share a network, means groups often come with knowledge of shared activity requiring specific terminology to describe jobs, educational mindset and specialism (Wenger, 1998).

Understood as narratives, a broader conceptualisation of discourse can be thought of as the power groups hold themselves or the power groups hold over others, different levels which may build

cumulatively to exert pressure from a macro level to an individual one (Thompson, 2007). From this perspective, narratives may also be understood as reservoirs that are held within networks, shared stories that may also be situated across globe-local networks (Thomas, Wareing, Singh, Stillwell Peccei, & Jones, 1999). Oppression defines the negative power – the bias that links negative ideas to specific groups – perpetuates the stereotypes and deepens the prejudice towards people within them (Thompson, 2007; Gladwell, 2008). Words are not static in their meaning; rather they are tools whose sense shifts and alters depending on the activity they explain, the depth of knowledge they imply and the shared understanding of a group (Wilson, 1956). These go beyond the spoken word and evolve continuously:

All languages and cultures are continuously in the process of becoming, in recreating meanings. There are no “finite” static languages as they constantly evolve as a result of language contact and interaction among people and groups, in relation to historical, political, and economic factors. As part of the effort to make meaningful connections and interactions, new language elements are created, used and exchanged. (Shohamy, 2006, p. 8)

By using language policy I wanted to highlight ideas from within the organisation, including those which stand against common heuristics or ideologies, those which tacitly exert pressures on us all (Schön, 1983, 1991): terminology, for example, that leads to debates in the field which are actually a battle of words defined differently by each speaker or group (Argyris, 1993). A vivid example relating to disabled people’s choice lies in Rob Grieg’s battle of the blogs with Rochdale Council over the meaning of community living and group home, as defined by Person Centred Planning (Greig, 2016). Importantly, as the debate failed to fully articulate, people with learning disabilities are often those in receipt of word games like this, but often have little power within them without articulate advocates. The debate also did not say that, whether or not they have impairments, disabled council tenants will have little say in the language used to define the terms of reference chosen in national debates of this importance. However, policies that define government strategy do impact the way they lead their lives. Quite literally their ‘homes’ maybe sold to different ‘owners’,

so effectively they will wake up in someone else's house. This explains why emancipation can be eroded by the technical complexity of language in the workplace; because conversations create power within the institutions where stories are told from the cultural perspective of each workplace (Thomas, Wareing, Singh, Stillwell Peccei, & Jones, 1999). Language in its completeness conveys culture through words, gestures, clothes, décor and art (Shohamy, 2006). More than tools with exact definitions, words can be used in different contexts to have different meanings (Austin, 1979; Spolsky, 2004; Ricento, 2006); therefore text has the more specific role of denoting ideas, power and status (Thomas, Wareing, Singh, Stillwell Peccei, & Jones, 1999). Using this structural dimension of power in combination with Schein's model of culture, we have a starting point from which to represent the different groups in which people can exercise their voice.

As Shohamy suggests, languaging develops around shared activity; put simply, the more we know about an interest or skill, the more specific and fluent we become in explaining its significant concepts (2006). Different interest groups will have conversations according to culture as ideas and technical know-how are woven into them and will require different shorthand for conceptual purposes (Moore, 2012). A narrative suggests a more fixed state than that of dialogue, which is more fluid and represents more fully what is negotiated in storytelling (Sennet, 2003). What matters emerges through the act of performance: narratives facilitate our ability to be positive about the future and plot a course towards it. In narratives, the interaction and the exchange of ideas create new opportunities – if and when we choose to let go and listen to the whole person. Behaviour is also communication within narratives: what is difficult to hear communicates pain and frustration, and the most eloquent speaker may be the hardest to hear (Lovett, 1996).

The use of language policy, therefore, helps explore those ideas that disrupt power, because storytelling 'that may look irrational or inefficient to the classical theorist may be perfectly rational

and efficient to the local criteria and *modus operandi* of the particular social context' (Whittington, 2001, p.27). Language and privilege can be viewed as the power structures held within the stories we tell, many of which are unquestioned (Thomas, Wareing, Singh, Stillwell Peccei, & Jones, 1999; Simpson & Mayr, 2010). It is not so much the voices within them, but the overall group story they convey that can amplify or diminish belief in mainstream ideas that most of us ignore. As stated in Eddo-Lodge's book *race* (2017), the debate about identity has changed, exploring discrimination and the character of marginalised groups must move on, because such explorations are an abuse of privilege that needs to end to make way for a more nuanced narratives about privilege (e.g. *whiteness theory*). For those groups marginalised by orthotoxic culture, narratives typically have an oppressive impact: it is this power that needs addressing.

As long as they're just out there, just a different group of folks, you won't have to deal with them. When you deal with them, culture turns personal. Culture is no longer just what some group has; it's what happens to you when you encounter differences, become aware of something in yourself, and work to find out why the differences appeared. Culture is an awareness, a consciousness (Agar, 1994, p. 20)

The power of the bias within the story told will build cumulatively from the position of the individual, to the group and across society more widely (Thompson, 2007). Disability equality with language policy help explore and define characteristics of power. For example, interviews give actors a thinking voice secured through dialogue – an opportunity of reflection for action. The interpretation of language and text provide a narrative that is 'not simply a question of adding a complementary source to match documentary evidence, it is more likely to challenge and subvert understanding of care and control' (Thompson, 2000, p. 8).

In previous work and research I have focused on language as a manifestation of power within organisations with regard to leadership activity, respect and empathy (Chapman, 2013). I had defined language as more than personal skill, seeing 'our words as interpersonal tools. In this way the threads of ideas that connect us can become a web of shared experience, woven from

conversation. Shared stories therefore become the thoughts that connect us. They thread through our relationships, uniting the social fabric of our lives' (Chapman, 2016). Geertz's ideas of webs of significance offered a way of seeing language as the culture that holds community together through shared ideas about practice (1973), allowing me to use language and culture as the articulation of evidence-based knowledge within a community of practice (Wenger, 1998). For example, as a general rule I observed that the terms 'disabled people' and 'people with disabilities' created a zone of tension – even conflict – between those speaking for people with impairments and those recognising their voice aligned with the disabled people's movement. I used the methods to help identify the authority in the voices of the community of interest, the empirical site, ReShape. A narrative can be viewed as a negotiated account told from a specific perspective, not authored by a writer but a shared story to be told by many tellers (Mauthner, Birch, Jessop, & Miller, 2002). The methodology of ethnography encompasses both emancipatory research and human rights principles, and methods that aligned with ethical considerations around disabled people who may sometimes face considerable disadvantage. I was enabled to draw on the specific character of organisational culture while preserving sense of 'expert gaze' and co-existence of entangled (or interwoven) multiple truths. While the focus on culture helps articulate inequality at group level and the impact of group culture – through language – on others (Thompson, 2007; Schein, 2010; Thompson, 2017), it is with an intended direction that would also secure greater respect for individuality of those involved.

As discussed earlier, language policy allows a corralling of the words found running free within a defined space (Agar, 1994). Therefore, among a fair few hours of chatter, small episodes served to describe a heightened insight into accountability. When inspiring practice is happening in the everyday moment, a description of that moment is pointless unless it is highlighted. The craft of storytelling in chapter six enables the common to become exceptional, if only once on a single

page. Using language policy as a theoretical lens allowed me to draw a circle around community of parlance in order to think about how they differed, aligned or interacted with other such community. In chapter eight, I theorise about the relative power of group voices, and their need to negotiate as a deliverer of service on the one hand, and as a recipient of funding on the other. It is in the most recent interviews, that conversations became more nuanced and more complex, when the taken-for-granted was laid out and assumptions exposed for deeper consideration.

Language policy is used as tool with which specific characteristics of narratives are compared and contrasted, and these elements of dialogue are then put forward as cultural signifiers of a human rights approach (Holtgraves, 2002). The method is synonymous with the activity that previously helped define language in relation to ableism in culture: language policy helps reveal meaning because ‘language is heavily contextualised and dependent on real-world knowledge’ (Holtgraves, 2002, p.33). Language policy was used to identify distortions of language in globe-local debates. Language in texts was examined to define the context in which people talk about disabled people’s human rights. In this chapter the focus is the issue of accountability and its definition within business. The research relates to directly to services delivering to disabled people, but since every service deals with disabled people if they serve people, it should not be seen as a legitimate definition of accountability unique to the disability sector.

3.7 Stepping forward

Thus far, the thesis has argued that more than being an intriguing oddity, the lack of voice of disabled people needs to be a question of epistemic value for the research community. From a legitimacy perspective, to be accountable to marginalised groups and the individuals identifying within the group, need to feel part of the common storytelling. In this chapter the choice of research tools are outlined because they help highlight the voices of disabled people and therefore fit an

empowerment approach. Rather than dictate methods, the ethnographic approach more specifically applies to being in the field, telling the organisation's story and explaining to others what I learned from the trip (Poole & Morrison, 2003). I chose methods that enabled co-construction, with the assumption that knowledge is held within groups such as organisations. I was keen for my presence to appear usual, being part of the typical group, adapting to circumstance, becoming familiar with *their* story and the deeper levels of understanding that shape their conversation (Punch 2005). The theorisation will arise later from the process of note-taking, making the tacit and the atypical explicit for the reader, by constructing an account from both within the organisation and against a background hum of influences from other institutions in the naturalistic tradition (Punch 2005). While traditional knowledge and common sense are not value-free (Ruane, 2005), the interpretative approach allows positive emotions to support the validity of the personal perspectives that emerge (Kline 1999).

In the chapter that follows, I start with the textual analysis to reveal the narratives of injustice imposed on the voice of disabled people. I use a *crip gaze* to make sense of what I read – the interpretive process to achieve an interpretation of texts. Exploring culture this way gives meaning to how disability is understood and conceptualised through the stories of workers working with disabled people (van Maanen, 1998; Silverman, 2006). The analysis enables me to articulate five narratives of injustice, which from a global-local perspective give a multi-tiered expression that helps deny disabled people their full entitlement to human rights.

Interlude

Jean knows little of the world. Global affairs are dealt with by others, despite the harm they cause her. Close to home, she feels the conversation is steered by those using big long words that have no meaning to her.

Jean was denied a primary education, allowed to watch others but not to join in. She is now judged on poor grades and few qualifications. She got no help, just disapproval, and often had to hide her shame in the face of ridicule. Thanks to stories in the papers, people seem to think she lives on a different planet. People assume she doesn't need to work. She reads that worklessness is her choice, and she feels hopeless knowing the obstacles. The chance of interview is slim, should she get the illusive call, she knows she is more likely to be offered voluntary work while the job goes to the next in line. She lives in fear, terrified by the demands on her. Should she be one of the 1 in 10 to get work, there is a double whammy: she will need to get up earlier and work harder. Spending more energy than most by lunchtime; the extra cost of effort is hers. While she can work harder than others to prove your worth, she will be paid far less for the chance.

When it comes to fitting in, Jean knows she is expected to fail. She feels she is continually rejected because her face does not fit. In the papers, she sees no faces like hers. When she speaks of rejection, frustration, abuse and fear, people back off. Confronted by disturbing truths others say they feel fear, shame and pity. Prejudice!

As teller, in the past, people like her have been hidden and dealt with harshly, their tales ignored or twisted to justify a wider rejection. Jean still suffers the results of this denial, although she may not necessarily know why this happens. She isn't a researcher and she isn't an activist. So while her feelings are trustworthy, they need to be written in ways that also reflect the values of research: objectivity, honesty, openness, fairness, accountability, and stewardship.

Slavery wasn't crisis for British and American elites until abolitionism turned it into one. Racial discrimination wasn't a crisis until the civil rights movement turned it into one. Sex discrimination wasn't a crisis until feminism turned it into one. Apartheid wasn't a crisis until the anti-apartheid movement turned it into one.
(Klein, 2014, loc 190)

Part 2

Chapter Four

Narratives of Injustice

4.1 Talking of rights

"It seems to me, that your power is a hidden power, because people only think of you as communicating reality, but in communicating reality, you construct reality." (Hines, 1988, p. 253)

In the last chapter the methods were outlined, responding to a methodology that seeks to weigh against the epistemic injustice in storytelling named as ableism. The resulting adjustment through evidence-based knowledge is extended in this chapter on human rights, which serves as a literature analysis, and aims to explore a number of texts that reveal the distortions which re-present disabled people unjustly. It is, therefore, a review that recognises that the story told about disabled people is often imbalanced, because the evidence-based knowledge that should apply to research is often stripped of a fuller articulation of an anti-ableism in textual accounts. The textual analysis that follows includes non peer-reviewed texts, so as to provide the personal experience and working wisdom that is typically missing in many other texts.

Having made a case for disabled people as storytellers, in accounts not shaped by ableism but an understanding of evidence-based knowledge, the following is a review relevant to a broader discourse on human rights. It is a textual analysis that goes further in trying to speak of the structure of ableism, in the context of a world influenced by globe-local, institutional and work narratives on disability. To do so it explores the different narratives used to talk about the human rights of disabled people that shape worldwide debates, discourses, conversation, and personal interaction. The next five sections set the stage – the societal landscape – by revealing the injustices in a language of culture that affect the reading of social reporting in the present day; because when accounts are offered in all the tellings of history, power is held within the relationships of conflicting agendas by stories that influence how these are re-told (Macintosh, 2002). The following sections address the silencing identified in Chapter 2, but go further to describe the civil rights

‘crisis’ identified by Disabled People's Organisation’s in the name of the disabled population – a failure to uphold entitlements to dignity and freedom that grew in intensity as a crisis in the public domain over the period of the research.

4.2 The case of missing textual evidence

In the following, using the lens of evidence-based knowledge I explore the distinctive nature of narratives surrounding the human rights of disabled people, more specifically, in Scotland. Here I examine the context in which disabled people’s authority has been subverted and their voices silenced, as the global inequality deepens the impact of an oppressive power on levels beyond personal experience. Thus, the mapping that emerges articulates a complex, contradictory, multiple, and random landscape against which the research will sit (Kozinets, 2015). The chapter serves as a snapshot of the present-day context, a globe-local or translocal presentation, which ebbs and flows in the fluid and ever-changing climate of world culture. I endeavour to provide a position in this flow, to expose the specific elements of narratives of injustice that contribute to orthotoxic culture. In doing so, more specifically, I seek to emphasise the ableism that some people may not see or understand – the harmful ideas that impact on disabled people’s wellbeing.

Looking back, the results of the textural analysis should not have been surprising. However, especially early on in the search I was taken aback by the stark absence of what I had expected as a paper trail. As I started writing about it I found it hard to introduce, the context explored in chapter two needed adding before this analysis could make sense. The texts that did deal with disability were skewed, mostly illness and impairment were conflated, disability studies were ignored and individual stories were stylised. Having set out to find a distinctive voice and evidence of interaction with networks of disabled individuals, it proved far more difficult than I had anticipated. The results of my analysis led me to understand that there are very few texts published before the

1950s that tell of the personal and working experience of disabled people. Probably because less than three decades ago disabled people were all but invisible on the streets (Berghs, Atkin, Graham, Hatton, & Thomas, 2017). Disabled people had few personal stories in the public domain, and largely they lived in institutions or behind the closed doors of private homes (Humphries & Gordon, 1992). A recursive loop has seen a shift backwards in public consciousness over the last decade (Goodley, 2014), in a climate where disabled people are subject to daily attacks and the nature of the crisis in its manifestation emerges from far wider vilification (Quarmby, 2011), hate and harassment. Even the most minor omissions and micro-aggressions are poisonous as they add up in a myriad ways to harm those exposed to them daily. These can include physical proximity, denial of gender, infantilisation, ridicule, disregard and banalisation. Easily dismissed by some as caring, teasing or friendly, this is clearly not how non-disabled people are treated according to those with an ableist sensitivity. As bloggers remark, the subtle messages communicated by these careless acts are negative and condescending (Lu, 2016). No doubt the product of bias, they are untypical in ordinary everyday exchanges, they are the very personal end of a more indistinct yet sizeable wedge driving hate crime (Quarmby, 2011). This wedge, when lodged deep in the spleen, is neither recognisable nor understood as the multi-layered juggernaut it is to those who can articulate it.

4.3 Five tiers of harm

An analysis of the narratives used in human rights discourse is important in order to explore more fully the layered structure of disabled people's oppression and to articulate the character of its negative power. Without an acknowledgment of the global, national, sector and institutional ableist ideas that litter our landscape, it would have been impossible to describe why ReShape's culture is so different in the way it places its trust in the voices of the people its workers support. Put another way, knowing there is a global inequality imposed on the disabled population that creates impairment in areas of poverty serves to highlight the personal importance of meeting human rights with financial amounts that compensate adequately for circumstances and assure wellbeing not just survival. And 'disabled people across the UK continue to face serious regression of many of their rights... Social protections have been reduced and disabled people and their families continue to be some of the hardest hit' (Equality and Human Rights Commission, 2018).

The meaning of vocabulary is explored here to articulate the distortion of global-local narratives. For example, when the word 'disability' is used, the term is employed to imply impairment, oppression, discrimination, prejudice and/or identity. The authority of my own judgement grew as I read through papers, books, and articles, and over time it became easier to judge whether an author understood any notion of ableism, disablism, disability studies or disability equality. I looked for writers' ability to differentiate between disability (subject), dis/ableism (oppression), disabled (verb implying receipt of oppressive attitudes and/or discrimination) and disabilities/impairment (illness, condition or difference). Of greater concern, say lawyers, is an exclusion of a disability perspective from public debate, a 'radio silence from the 'mainstream' human rights bodies on this issue – feeding the unfortunate impression that violations of disabled people's rights are not 'real' human rights violations' (Broach, 2018).

The following sections identify five distortions of the narratives about disabled people's human rights.

1. **Global** narratives, show a lack of nuanced terminology to describe the north/south effects of globalisation led by economic inequality, and the great size of the disabled population, making the experience of disability a product of unsustainable growth.
2. **National** narratives within domestic debates that tend to flatten a far more complex articulation of community that has a bearing on the interaction between identity and group membership.
3. **Market** narratives that conflate issues of business with community interests and thereby extend dominance over the disabled population in matters of relationships and citizenship.
4. **Non-representative** narratives influenced by market ideology, that further pushing disabled people into the consumer role of passive recipient of the commodification of services.

Finally, **personal** narratives rather than individuals that become stories stripped of the above layers – ones that focus on vivid cases or particular crises that are then skewed by the likeability or heroism of the disabled storyteller.

The five sections refine the layering already identified in section 1.5.2 about narratives and power, by adding local and community perspectives to the personal, structural, and cultural ones identified as oppressive (Thompson, 2007). The patterns of communication described above also follow the five primary framing strategies suggested by the Frame Works institute: Unframed Facts and Numbers, Description Instead of Explanation, Problems Without Solutions, Crisis Stories, and Vivid Cases (Frame Works, 2016). More specifically these frame the distortions in the broader storytelling about our world, the trust misplaced in those privileged by advantage.

4.3.1 Global inequality

The first distortion is situated at a global level and relates to the vast number of disabled people on earth affected by ableism. Looking at the literature about global sustainability, and emancipation more specifically, I found nothing that addressed the impact of growth and inequality on the disabled population *per se* (Speth, 2008; Gallhofer & Haslam, 2011), which is odd because emancipation is dependent on wellbeing factors that can be broadly described as having sufficient wealth to meet needs to prevent illness (Wilkinson & Pickett, 2009). Yet bizarrely, narratives on the topic of disability focus largely on illness, not wellbeing. This medical view of disability not only effaces the link between impairment and unsustainable growth driven by materialism, but is reinforced by a colonial imperialism that deepens the inequality between rich and poor countries. Poverty related to geography and lack of status dumped on those viewed as impaired, disables members of this marginalised group. As past activists have said: ‘imposed on top of our physical impairments by the way society is organised to exclude us. In our view, it is only the actual impairment which we must accept; the additional and totally unnecessary problems caused by the way we are treated are essentially to be overcome and not accepted’ (UPIAS, 1975, para. 16). The skewed storytelling helps denials that the inequality that hinders wellbeing, in some cases imposes certain types of impairments too. While disabled people are expected to rise above their circumstances in the global-north, further injustice is laid at the feet of disabled people in the global-south, whose experiences of being disabled are not linked to violence caused by worldwide instability.

...the legacy of invasion, colonisation and globalisation... has left many disabled people in the global-South living in dire conditions of poverty. Given the close connection between poverty and disability, it could be argued that a redistribution of power and wealth both between rich and poor countries and within poor countries could have more impact on the lived experience of disabled people in the global South than would human rights legislation. (Meekosha & Soldatic, 2011, p. 1389)

Put another way, the impact of the global context is significant everywhere, because it is the weight of inequality imposed on the disabled population worldwide that disproportionately harms those most disadvantaged by it. Where the disabled population as a marginalised group are mentioned, or viewed as a super-group, it denies the explanations of variations that might be most relevant to disabled individuals' wellbeing. On a global scale, the drive of individualism, not individuality, imposes a paradox that appears contradictory in the context of human rights. While individual needs have been highlighted as an entitlement, these are often confused with the wants and desires that fuel unsustainable inequality. Driven by consumption, this threatens wellbeing unequally (Seligman, 2002; James, 2007; Wilkinson & Pickett, 2009). As the Director of the UCL Institute of Health Equity explains with reference to health more specifically:

The central issue is that good conditions of daily life, the things that really count, are unequally distributed, much more so than is good for anything, whether for our children's future, for a just society, for the economy and, crucially, for health. The result of unequal distribution of life chances is that health is unequally distributed. (Marmot & Bell, 2012, loc 108)

In the United Kingdom health inequality is visible at a glance at the figures. Given the current calls for the Government to hold itself accountable towards disabled people with regard to welfare reform, it is surprising that figures have not been updated since 2014:

- Over a quarter of disabled people say that they do not frequently have choice and control over their daily lives.
- A substantially higher proportion of individuals who live in families with disabled members live in poverty, compared to individuals who live in families where no one is disabled.
- 19% of individuals in families with at least one disabled member live in relative income poverty on a 'before housing costs' basis, compared to 15% of individuals in families with no disabled member.
- 21% of children in families with at least one disabled member are in poverty, a significantly higher proportion than the 16% of children in families with no disabled member. (Department for Work and Pensions, 2014)

The prevalence of impairment rises with age: 6% of children are disabled, compared with 16% of working age adults and 45% of adults over 65, yet most adults with significant impairment do not

consider themselves disabled. Disabled people are around three times more likely to hold no qualifications compared with non-disabled people, and around half as likely to hold a degree-level qualification. Over a quarter of disabled people say that they do not frequently have choice and control over their daily lives. Disabled people are significantly more likely to experience unfair treatment at work than non-disabled people (Department for Work and Pensions, 2014). In 2008, 19% of disabled people experienced unfair treatment at work compared with 13% of non-disabled people. Disabled people are significantly underprivileged by society's organisation according to DWP reports (Department for Work and Pensions, 2014) and 'Demos estimate that in the UK disabled people will lose over £9 billion in welfare support in the next five years and that these policy changes will hit disabled people harder than any other group' (Briant, Watson, & Philo, 2013, p. 875). Around a third of disabled people experience difficulties related to their impairment in accessing public, commercial and leisure goods and services. Recent reports state that government intervention is being run with scant regard to disabled people's feelings, and imposing fear and shame, in the pursuit of financial aims (Department for Work and Pensions, 2014).

Due to global inequality the global-north tends to indulge in the pleasures of materialism, while the health of the population in the global-south is compromised. This inequality will have a compounding impact on all populations, as a structure similar to those described by Thompson as compounding levels of power, sits above the consciousness of individuals, groups, institutions and society (2007). Furthermore, it is the capitalist pressure owed to previous colonial powers that enables a sensitive articulation worldwide injustice that also hinders the human rights of disabled people globally. Although, there are no class, race, gender specifications in the occurrence of impairment, there are clear patterns in:

... the emergence of disability in the wider history of class society in general and capitalist society in particular. [this book] takes the view that understanding its development, roots and nature as a

particular form of oppression is key to the wider project of human emancipation. (Slorach, 2015, p. loc 111)

As the evidence from the Whitehall studies suggested, money is less of a differentiator in terms of health than an ability to make decisions (Marmott, 2015). For the opportunity to choose, a wide agenda of options needs to be available to satisfy a fair access to education, employment, housing, leisure to the wellbeing of marginalised groups (Nettle, 2005). On a global scale, Portugal has been named as the country that best satisfies the relationship between income and wellbeing (Layard, 2005). The positive impact of increasing earnings ceases to add to happiness when needs are met, for while money is critical to resilience, provided relationships and engagement, the added pleasure it can fund tends to be addictive (Layard, 2005; Gilbert, 2006; Seligman, 2011). And while the data may hide how this affects the disabled population as relative poverty is not highlighted by segregated data (Criado Perez, 2019), materialistic narratives do reinforce an overwhelming view that progress is good for humanity.

The accelerating nature of global inequality also comes with warnings that growth can be harmful for groups such as disabled people (Speth, 2008). Indeed, side effects of production can be devastating for human communities, and while an unquestioned belief in the efficiency maybe desirable for business, the impact can be lethal to those most marginalised methods of production and side-effects of consumption (James, 2007). Clearly the *unquestioned* nature of consumerist ideas reinforce the orthotoxic culture in which a market conversation that measures growth in financial terms holds power. Individualism conflated with minimal view rights as participation in work, further reduces disabled individuals to consumers whilst still viewed as non-productive.

With narratives of consumption hidden from view, obscured by a belief that all growth is good, sustainability is equated to a duty to participate in economic activity irrespective of harm or disadvantage. Furthermore, evidence suggests that it is in the area of working life from which the

disabled population are most excluded, leaving a gap in the conversation where their authority should be found. This mixed message adds to the idea that there is a linear continuum, to which *all* disabled people fall at the inefficient end, and end up being blamed for their rejection from the workplace (Slorach, 2016). Denied equal access to employment, disabled individuals are then pushed aside as consumers – despite the *purple pound* – as goods and services tend to be inaccessible to many (Slorach, 2016).

For those in the global-north, a conversation about human rights may be experienced as more liberating in the context of wider market narratives, but for not those for whom the experience of harm imposed by the impact of inequality that drives poverty in the global-south. From a worldview perspective human rights violations ‘are not accidents; they are not random in distribution or effect. Rights violations are, rather, symptoms of deeper pathologies of power and are linked intimately to the social conditions that so often determine who will suffer abuse and who will be shielded from harm’ (Meekosha & Soldatic, 2011, p. 1386).

4.3.2 National narratives that flatten debates

The second distortion occurs at a national level, and helps further highlight differences between Scottish and English culture, in the way debates about welfare are discussed in public. With societal inequality comes the responsibility of government and services, which becomes furthermore problematic for individuals within a widespread market culture (McKnight & Block, 2010), more saliently in documents where a predominantly market narrative conflates professional costs with community interests. It seems that the belief in the neutrality of a market narratives has had an impact on how we talk about community and how we think about democratic action (Craig *et al*, 2011; Minkler, 2012); as people become ever more passive in their consumer roles they become

less engaged in their own locality, and less able to empathise and demonstrate respect towards each other (Baron-Cohen, 2011).

In the United Kingdom, *The Guardian* highlighted during the UN Committee on the Rights of Persons with Disabilities enquiry that the ‘government is failing to uphold disabled people’s rights across a range of areas from education, work and housing to health, transport and social security’ (Butler, 2017). Within a culture reflecting overwhelmingly market narratives, the wording of state legislation also conflates personal capacity and responsibility to work (Wiggan, 2012). Legislation supports individual choice, rather than challenge the national narratives, as ‘the principal objective of government is not to enforce individual rights, rather it is to sustain the types of institutional configurations that promote equality of power’ (McPhail & Walters, 2009, p. 69). The political narrative often ignores the lack of fairness in numerical measures despite their scale, and remains thus ‘disconnected from the possibility of accountings complicity in human rights abuses... If the idea of human rights does potentially represent a valid way of protecting some of the most vulnerable within society from abuse and exploitation, then we should be concerned about those organs in society that can affect both their promotion and violation’ (McPhail & Walters, 2009, p. 56). Put another way, as market narratives rarely destabilise growth, they fuel the insatiable nature of human greed. While the pen-pushers celebrate materialism, by expressing it as a right, those at the edge fall victim to comparison while struggling to survive.

For those on the edge-of-the-edge, the distortions within debates add to the impact of inequality on the health of disabled people (Wiggan, 2012; Beatty & Fothergill, 2013). The narratives used in the media are often uncompromising. In the left-wing press, the message is clear that disabled people are burdens on society (Briant, Watson, & Philo, 2013), and equally, the right-wing press has helped entrench the view of disabled people as burdens, ill-deserving of the benefits to which they

would be entitled if they chose to work (Hughes, 2015). As disability rights policy wonk Liz Sayce, former CEO of Disability Rights UK, makes explicit in the Guardian:

... this means “extreme inequalities” are exacerbated, says Sayce. It feeds into an unacceptable “othering” of disabled people, which in turn hinders further progress and contributes to a pattern of disability being couched in terms of vulnerability, rather than rights and “equal citizenship”. (O’Hara, 2017)

In national debates, fed by the ideology of consumerism (James, 2007; Slorach, 2015), the commodification of services delivered to disabled people has further entrenched an economic narrative focused on cost, not rights. The added fear of scarcity, linked to an austerity narrative, facilitated a distancing from questions of human rights abuse (Briant, Watson, & Philo, 2013; Goodley, Lawthom, & Runswick-Cole, 2014). Disabled people are specifically subject to a type of alienation in employment for example, the double whammy of being thought of as workshy **also** brands them as less human (Green & Lawson, 2016; Qa Research, 2017).

Building institutions was a cost-driven solution to wordlessness. An irony, because this institutionalisation came of the relative riches in the global-north, therefore built on the colonisation that funded the industrial revolution (Goodley, 2012), which funded the workhouses and asylums that were erected to house and care for the most disadvantaged (Oliver, 1990). Disabled individuals were moved away from society, from communities and families, and a labour force that needed to very efficiently fuel Britain’s growth as an industrial power (Oliver, 1990; Slorach, 2016). Within this cultural context the traditional models of disability seem less arcane, having replaced a view impairment as punishment from gods or higher powers, the paid worker had science and was therefore given power. However, the market narrative is powerful when it crosses boundaries into health and social care, for example. Conversations about cost strip away elements needed for wellbeing in ways that threaten disabled people’s entitlement to participation in other areas of life. This unfair treatment caused disabled people and their families to be persecuted and victimised as

they pushed to safeguard their rights, as exemplified by responses to The Learning Disabilities Mortality Review Annual Report 2017 (2017).

Rare is the story told about those worst affected by policy, the austerity measures and welfare reforms that reproduce hardship and disadvantage, whereas an acreage of pens seem poised to be more disgusted by fashion than by the causes the pain of those suffering hardships and disadvantage. Celebrity's ink only adds to the greater silencing, as this Guardian articulates:

This is the biggest benefit cut that you've never heard of. The newspapers will waste gallons of ink on Candice Bake-Off's lipstick and Cheryl's apparent baby bump. But about a government policy that could disrupt hundreds of thousands of lives, there is near silence. (Chakraborty, 2016)

This absence of ink is noteworthy in regard to local trends. As an example, in both national and organisational debates, disabled people's employment is often seen as a failure to secure a job. This type of conversation fails to articulate the minute chance of a disabled candidate's success. However, statistics reveal another reality: 'In January 2016, the UK employment rate among working age disabled people was 46.5% (4.1 million), compared to 84% of non-disabled people' (Smith, 2016). While numbers *can* speak volumes, they do not always express the circumstances of personal failure in terms of facing a complexity of bias. The cultural 'norms', and societal expectations, that are often beyond the applicants perception. 'I know I'm suitable for the job' versus the stereotype the 'disabled people will never achieve excellence'. These negative bias of stereotypes are documented (Barnes, 1991; Gladwell, 2008), but the specific character of ableist assumptions, believing disabled people are useless, costly, and often off sick, are rarely laid out to be contradicted by evidence:

This means that 49.2 per cent of disabled people between the age of 16 and 64 are in employment. In the same quarter the employment rate for non-disabled people was 80.6 per cent, giving a disability employment gap of 31.4 percentage points. (TUC, 2018)

Language here is a key issue, not only is how we tell of disability, but how those that speak – or not – are perceived by others and judged by society. Any lack of any real medical knowledge until the mid-nineteenth century meant that many people were misunderstood, and therefore spoken **for**: people with speech difficulties were considered idiots, and locked away under the 1913 Mental Deficiency Law (Bourke, 2011). This legacy has endured, buildings and institutional mindset equally unwieldy to change, and where research evidence and working wisdom *should* counter misguided logic, misrepresentation still persists.

4.3.3 A working mindset and institutionalised arrangements

The third distortion, one situated within working and their educational narratives, relates to the way knowledge is presented without sufficient anti-ableist thought or critique, so institutional discrimination remains deep in the weave of texts and associated materials (McPhail & Adams, 2016). So the marginalisation of disabled people and the silencing of their experiences is perpetuated in the very way teaching is organised and disciplines are taught (Dolmage, 2017). Many subjects still do not acknowledge intersectionality (Ahmed, 2017): some do, but miss out disability or refer to it less fully (Sandhal, 2003). Even fewer, I have found, call on multi-disciplinary perspectives to challenge assumptions implicit within a working mindset. Yet, reinforced by the welfare debates discussed above, narratives without a balanced view of a disability perspective have an impact create multiple forms of prejudice in the lives of disabled people (Finklestein, 1999; Coleman, Brunell, & Hauge, 2014). Thus lack of awareness, biased knowledge, and poorly understood insights lead to workers imposing limited options and many barriers on disabled people that restrict choice - and ultimately their freedom. For example, where a doctor views disability as illness in need of a cure, or teaching practice that marginalise learners with Special Educational Needs because they are perceived as inferior in a context defined by one dimension of intellectual ability (Gardner, Csikzentmihalyi, & Damon, 2001; Dolmage, 2017).

Across the literature addressing a working audience, articles on disability appeared predominantly in those journals geared to the medical disciplines. The word 'disability' used to mean condition or diagnosis, in three quarters of 606,057 abstracts, where the words were found to mean illness. When subdivided, the literature falls into 'impairment' specific journals used phrases typifying normalisation (recovery/getting better) or otherness (they or compared to persons with no impairment). This focus on impairment reinforces the idea that disability is an individual's problem, to be cured or treated separately, decisions made by workers on behalf of patients. Unsurprisingly, the voice of the clinician appears clearly in text where medical workers hold the power of the pen. The conflation of impairment and illness is often found in health related literature, leaving the word 'disability' undefined in terms of ableism: stereotype, prejudice, privilege, barriers and inequality. Across many disciplines, there have been flurries of papers published in areas where new legislation has been imposed. However, the implications of social model of disability have been poorly explored, and while contested the model still is an indicator that disabled people's authority is recognised and therefore its absence is hard to ignore.

Whose issue?



Figure 4.1 Intersectionality

of disability as illness, an individual problem at best ignored. Few were the texts that seemed to have searched for equivalence to feminist, anti-racist or queer theory, in their storytelling. It appeared that disability is put on an alternative spectrum altogether, with little acknowledgement of cumulative or the privileging aspects held within a structured oppression. Intersectionality needs to explain and expose the hidden aspects of multiple identities that are significant in order to help counter the narratives imposed by working ones driven by capitalism (Slorach, 2015). The compounding aspects of discrimination have overall significance because disabled people's rights have been weighed alongside others – not as a separate or alternative to a defined population with specific characters and interests. Intersectionality is not about debating whether individuals from some groups have a better or worse experience than others, but understanding that hardship and disadvantage are structurally multiple and cumulative. The voices of gay and disabled civil rights activists in academia have origins in activism, sharing a history of injustice, both have been pathologised by medicine, and 'demonized by religion; discriminated against in housing, employment, and education; stereotyped in representation; victimized by hate groups; and isolated

Outside disability studies ableism is rarely explained in an intersectional way. Yet, intersectionality, named by Crenshaw (Carastathis, 2016; Ahmed, 2017), is critical to understanding the full extent of disabled people's marginalisation in terms of human rights. Because the layers of inequality, discrimination, and prejudice levelled at disabled people – compounded by factors of gender, race, class and poverty – affects identity (Kafer, 2013). I came across numerous texts that spoke

socially, often in their families of origin (Snyder & Mitchell, 2006). Both constituencies are diverse in terms of race, class, gender, sexuality, religion, political affiliation, and other respects and therefore share many members (e.g., those who are disabled and gay), as well as allies' (Sandhal, 2003, p. 26).

The possibility exists, for example, that facing sexism **and** racism may mean a member of multiple marginalised groups may feel exposed to many kinds of prejudice at once, a salient point because people's identities are multiple and fluid. For example, a disabled man may be seen as *predominantly* unproductive, a disabled woman *predominantly* as less intelligent, but a disabled woman of colour's experience may be ignored completely. Defined in the Macpherson Report, working knowledge as institutionalised oppression, is not about the labelling of individuals in receipt of racism, for example, but 'the collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantage minority ethnic people' (Macpherson, 1999, Para. 6.34). Viewed as Institutionalised ableism is equally about culture, the character of an institution's values and the attitudes of its workers. Like 'whiteness', group defines privilege, with able advantage bestowed on the non-disabled population through institutional structures that maintain power, resources, accolades and relationships, through activity and processes that continue unequal outcomes for disabled people (Bhopal, 2018). It is this access to cultural and social capital that can influence working mindset and codes of practice.

A number of cases have appeared in the media recently concerning the deaths of people in residential facilities (Toppo, 2018). These cases have been unbearable to follow, most significantly because of the language used by workers speaking on behalf of large organisations when dealing

with the private grief of families. Workers imposed boundaries, holding up a shield to prevent personal attacks or individual blame, while on the other hand paradoxically transgressing the personal pain of family members. The distortion seems to suggest that while privileged pen-holders continue to perceive disabled individuals as untrustworthy and easily dismissed as authors, they will continue writing narratives that best serve by those speaking on disabled people's behalf.

4.3.4 Groups and privilege

The fourth distortion occurs at local levels and relates to the way the group is perceived and their disadvantage named. 'Able-bodied' is often used to define non-disabled people, but unfortunately the wording poorly conveys that ableism is not about impairment, but the unearned privilege of those not having to cope with institutional discrimination and the disadvantage of inequality (Pease, 2013). I came across a shocking example of human rights denial in a passage in a book on Special Educational Needs that implied that disabled people's entitlement could not be upheld because there were already too many groups asking for human rights (Farrell, 2010). In the same publication, Shakespeare, a leading author in disability studies, is misquoted and the social model of disability discredited rather than critiqued. Non-disabled privilege in the academic form is still ableism. Examples are frequent, but the way disabled people's lack of privilege is largely ignored often in favour of a storytelling that backs more common stereotypes suggest homogeneity within the group that can deny a collectively held pride.



Figure 4.2 #SayTheWord 'disabled' tweet

Furthermore, while I often hear from workers that respectful language is too difficult or hard to find, I found the tweet above within seconds of writing the last paragraph. It seems far more likely that workers do not bother, and the voice of disabled people is ignored in conversation because they are not trusted. Therefore, even the narratives relating to their own interests are easily twisted in the more common market narratives driven by a neoliberal ideology. Similarly, disabled people's storytelling is largely effaced by issues relating to economy and education discussed in section 4.3.2 above, from which they are so often excluded [chapter two].

When considering why the word 'inclusion' was chosen by disabled people to represent culture that was neither segregated or integrated (Nind, Sheehy, & Simmons, 2003), it was to represent the community aspect of belonging. As a shorthand, '*Community*' as used here is about the experience of belonging. We are in community each time we find a place where we belong. The word *belong* has two meanings. First and foremost, to belong is to be related to and a part of something. It is membership, the experience of being at home in the broadest sense of the phrase. ... To belong is to know, even in the middle of the night, that I am among friends' (Block, 2008, p. XII). It seems word choice can be a deliberate attempt to right a historical wrong. Community stands against institutionalisation, particularly as disability services have their roots in hospitalisation, and more specifically the segregation of people with significant impairments (Manji, 2018). The 1913 Mental Deficiency Act, not yet repealed, acted as a method of detaining those deemed to be idiots, imbeciles, deficient, and feeble-minded (Oliver, 1990). It is understandable that the language of the disability movement has a community orientation as words have been chosen to describe shared interest, a need for belonging in the face of marginalisation. Unlike other civil rights movements, the disabled population has found it hard to come together, to find its voice and place, and has been slow to gather allies, probably because of the belittling and infantilism linked to its prejudice (McRuer, 2006; Hall A. , 2016). Rare are the non-disabled advocates willing to follow disabled

activists' leads, with workers more generally preferring to reinvent a wheel from their own position of privilege.

In matters of wellbeing, for example, when it comes to disabled people's interests, the non-specialist literature omits to mention the need for choice that is fundamental to resilience, and alleviates the hardship caused by layers of cumulative oppression (Huppert, Baylis, & Kevene, 2005; Layard, 2005; Diener, 2008). Given the increasing intimacy of the world media fill our screens, the narratives that interrupt our days are intensely personal, and deny the local inequality in favour of individual capacity (Fine, 2010). So stripping the multiple negative circumstances, or omitting complex explanations, from a damning description moves the eye away from the truth in the story. With the unsustainability of compulsive spending and endless upgrading to new models, this adds to the strength of the corrosive impact of a market narrative that impacts on those most disadvantaged more than other.

In matters of human rights, UK Policy has been unfair, affecting the most marginalised, those most disadvantaged and the poorest:

These findings also validate multiple reports by United Nations Committees who have been shocked and horrified by the regressive nature of UK Government policy. These findings also help explain the unusual increase in the overall death rate and the high rate of suicides by disabled people subject to the Government's misnamed 'welfare reforms'. (Centre for Welfare Reform, 2017)

The very focus on individual entitlement viewed as a human right for many has become increasingly conditional on merit, and who is perceived as deserving is entitled to rights. Written in policy, this approach to hardship imposes poverty squarely on the disabled population (Wiggin, 2012; Ryan, 2019). While many have explored the impact of media on broader narratives on disabled people (Briant, Watson, & Philo; Barnes, 1991; Crow, 2014), the vilification is imposed on disabled people across the political spectrum of the welfare debate (Hughes, 2015). The bias held in

personal deficit also distracts from an inclination to take the disadvantage that disabled people endure specifically in public conversations, where privilege of the group can speak louder than the cultural and societal oppression others face. Added to which, the recent explosion of interest in positive psychology and its power to grant individual happiness leaves many believing that overcoming barriers is a matter of personal choice (Sang, 2017). Again the stereotype of the courageous overcoming adversity means disabled people need to work harder, while the more privileged need to do nothing but praise overcoming adversity.

Since the emergence of the disability movement the voice of disabled people has amplified: with this strength, and despite huge resistance, a voice has risen, literature has burgeoned, and there is no denying that the rights of disabled people *needed* to be taken more seriously. Language has changed too, acknowledgement of the social model of disability has meant defining ‘disabled’ as a verb, the impairment the difference and dis/ableism the type of oppression. However, resistance still exists, with those with a paid-pen not adopting the subtlety or the self-reference. I have lost count how many times *I* have been corrected, despite my knowledge and experience. As Titchkosky puts it: ‘Even the slow-to-change Government of Canada has, in the last 30 years, shifted its words (its images): from the incapacitated, to the disabled, the handicap, to handicap people, people with challenges, to the now ever-popular (and often enforced) ‘people with disabilities’ ...One day, the Government might even entertain the suggestion by those in the disability rights movement that there is a good politics and pride in calling ourselves ‘disabled people’” (Titchkosky, 2009, p. 76).

While the media swings between describing disabled people as being ‘the same’ or significantly ‘different’, wording could articulate a far more complex situation (Bogart, 2017). Given the number of impairments, and their impact on the person or the reaction of others, any scale or linear continuum of what is normal is nonsensical (Shakespeare, 2006). On the one hand, many disabled

people live unencumbered by their difference but face huge physical, systemic and attitudinal barriers. On the other hand, others can feel overwhelmed by an experience very few will ever have to endure. Chronic pain, for example, can be compared to acute illness, but is different as it may not be curable and medication can bring equally painful side effects. To one end, all pain is human, to the other severe or unending pain does affect life, critical pressure to personal crisis.

The issue here is that a formal language, more suited to an institutional setting, is usually extended in groups formed around interest. In these spaces, where hierarchy is typically non-existent or very informal, the ‘rules’ applied to disabled members reflect more of a market terminology than for typical non-disabled members. This bureaucratic approach to disabled individuals is often laid on top of the existing prejudices they may face. There are few circumstances that can immunise against crises, but the critical pressure created by feeling excluded or treated differently can make people ill. The exclusion experienced by being held apart from existing networks can heighten sensitivity and reduces control (Huppert, 2005). In a ‘needs-led’ culture, so common to service and government sectors, overemphasis on labelling has forced much attention has on negative power, implying that power can be given or taken, and turning empowerment into resistance against dominant ‘oppressor’ groups rather than creating personally affirmed or group strength (Diers, 2004; Thompson, 2007). Dominant groups then maintain their position, which articulation of the complexity is hidden, leading people to unwittingly collude to maintain their dominance (Pease, 2013).

4.3.5 To each individual many stories

“Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world.” Eleanor Roosevelt

The fifth, and final, distortion is situated at an individual level, and conveys the way a personal voice, through the likeability of the narrator, can be dismissed or exaggerated in order to fit with stereotypes imposed on the disabled population more widely (Barnes, 1991; Crow, 2014). To explore the issue, I looked at texts that failed to frame storytellers in the context of a global, working, and local ableism, and therefore did not take into account their impact on the individual's personal experience. For example, the common trope of triumph over adversity where tragic figures are used to give a heroic spin on the survival over circumstances, creating the illusion that adversity is minimal and can be overcome through personal effort (Crow, 2014). With contemporary social media, the globe and local merge seamlessly at the click of a button, and everyone is judged on appearance, not circumstances.

The social narrative is a war of clashing sound bites, rather than a tapestry of perspectives telling a rich tale. Against the last paragraph's fractured narrative, disabled people also face a uniquely specific identity, because 'it resists change and cure. It is not chosen, and therefore it is outside of the dominant ethic of choice' (Davis, 2013, loc 572). Despite significant progress after legislative change in the nineties, things have felt harder for the disabled population in recent times (Goodley, 2014), and the situation appears to be getting worse:

While progress has been made in some areas, the overall picture emerging from the data is that disabled people are facing more barriers and falling further behind. (Equality and Human Rights Commission, April 2017, p. 7)

Hiding in plain sight are small acts of rebuttal that hide a multitude of stealth crime: disabled people denied jobs, turned away from restaurants and pubs, refused service in shops and services, rejected as homeowner or lodgers, failed as pupils and students, and frowned upon by in-laws... (Campbell & Oliver, 1996; Quarmby, 2011; Swain, French, Barnes, & Thomas, 2014; Crow, 2014; Slorach, 2015). Clearly, though, this is not a new problem, there has been a 'failure of much of the media to explore how the cuts are affecting disabled people, the reluctance to criticise government policy,

and the frequent representation of some disabled people as undeserving of benefits is a highly damaging situation, compounding the material effects of the cuts themselves (Briant, Watson, & Philo, 2013, p. 886). Those already struggling to survive under enormous pressures often feel a sense of hopelessness (Hughes, 2015). Whether it is the vilification within the right-wing press or the dehumanising characterisation of disabled people as objects of pity depicted by the left wing, the widespread nature of negative storytelling adds to the landscape around us – an omnipresent narrative that is destructive and corrosive to human existence (Briant, Watson, & Philo, 2013).

The stories we tell and the voices within them amplify or diminish the beliefs we have and the ideas that hold most weight, leading to unconscious habitual thought that affects our thinking in ways of which we are unaware (Thomas, Wareing, Singh, Stillwell Peccei, & Jones, 1999). For those groups marginalised by the negative ideas, the louder conversations will have an oppressive impact, and may carry messages that are damaging to individuals. Understood as power, these voices proclaiming the accepted truths of the society we live in dominate – sadly, often these messages are not identified as prejudice by the people they refer to. The power of the bias within the story told will build cumulatively from the position of the individual to the group and across society more widely. This grand narrative supports a powerful structural oppression and reinforces the cultural norms of its acceptability, leading to internal dialogues that become intensely oppressive to the individual (Thompson, 2007).

As Crenshaw explains in relation to racism, her experience of a lack of voice in the courtroom has led to lack of an explicit character for many of the multiple aspects of discrimination, and the worrying observation that individuals are compared to a mythical ‘other’ (Carastathis, 2016). As racism is in a white person’s experience, periods of social injustice are invisible in the lives of many people who live amid the drips of negative daily narratives. As Pease suggests, when we look at our

own reflection in the morning, many of us do not see our own privilege (2013). Many non-disabled people do not have to ask upsetting questions about their contribution to the world and productivity at work, or anticipate how they may be seen as a problem to others.

Asking the question “what is disability?” prompts a range of different answers. For most people the term refers to a range of limitations in the mental or physical functioning of individuals—an approach reflected in most of the current disability-related legislation in Britain and elsewhere. The first chapter of this book therefore traces the development of the term and its associated meanings, addressing in addition the related and often thorny question of terminology. (Slorach, 2015, loc 111)

Sadly, diagnosis becomes a personal signifier, one that requires identification. In the place of individual accounts, whether personal, working or academic, I found lots pertaining to illness and told of a medicalised view of disability. It is not that storytelling is always good. As the TED talk of Msimang (2016) warns, stories can give the illusion of solidarity without highlighting the bigger picture. The perspective of the structure of opportunity is important. As I have outlined above, nuanced narratives must include the impact of the global inequality, institutional culture and attitudes. Otherwise, the behaviour of a protagonist out of context can make them dislikeable, because not caring about a disagreeable character gives the reader/listener an opt-out box – a loophole giving permission to ignore any moral obligation to consider what shapes a personal story. This silences the author and erases their tale. Personal experience is quashed if it isn't brave, courageous or inspiring.

Sometimes, it's the messages that we don't want to hear, the ones that make us want to crawl out of ourselves, that we need to hear the most. For every lovable storyteller who steals your heart, there are hundreds more whose voices are slurred and ragged... we can't afford to ignore them simply because we don't like their protagonists or because that's not the kid that we would bring home with us from the orphanage. (Msimang, 2016)

Articulating an individual's situation in a wider narrative acknowledges the all-pervasive toxicity demands an ability to know the dis/ableist character of the grand narrative affecting a person.

Finding the hidden voice is important as it expresses an internal narrator experience, that of internalised oppression and hopelessness, so typical for many disabled people who feel beaten by circumstance. As stereotypes, commonplace in the world, make it a toxic place, individuals respond to this story through behaviour that itself becomes a source of blame (Chapman, 2011)

A multi-layered account, is typically ignored but can become the core of activism, in the sense of being conscientious of our own privilege in the structure of oppression (Freire, 1970). Disabled people's voices are not ones we often hear. They carry stories that are hard to listen to, because despite being far from unusual, the pain they carry is sadly at odds with a more common belief that suffering is rare (Fricker, 2007). Labelling impacts on self-image and erodes resilience, which can be viewed as a reserve or flexibility to be employed in time of need, crucial to maintaining health in the present and in ensuring positive emotion going forward (Huppert, Baylis, & Kevene, 2005). For any group, this means that feeling pleasure on a regular basis and being engaged in shared activity and group life in the short term promotes the 'cognitive processes and builds coping resources that lead to later resilience' in the long term (Huppert, Baylis, & Kevene, 2005, p. 321).

People with disabilities should be asked to express their views, as concerns for daily challenge, future goals, social inclusion, and interpersonal relations. They should be involved as consultants to point out aspects of the social environment to be implemented, removed, or changed **in order to empower their status as citizens**. (Delle Fave and Massimini, 2005, p. 390)

Equally, Crenshaw also gives a name – the 'trapdoor' – to the beneficial aspects of privilege an individual may be lucky to experience *within* a marginalised group, for example, a disabled individual who unlike many has received a particularly good education. Together, the metaphors envisioned by Crenshaw are hugely important here in terms of positioning the piece towards a post-humanist philosophy, although its ramifications sit beyond the scope of the research. I found this helps to highlight the complexity of diversity, as considering these metaphors enables a disruption of the reifying idea that disabled people and non-disabled people sit at different ends of a spectrum, and they also stand apart from those in other marginalised groups (Davis, 2013; Goodley, 2014).

4.4 Storytelling: dis-story and allies

The Mass Behind the Single Voice - Virginia Woolf

In storytelling, the performance brings energy for change and people respond to stories with more enthusiasm than policies. The negative focus which links a deficit concept with disabled people has been detrimental to the perception of them as trustworthy leaders in their own interests – of political significance more widely. More importantly, storytelling is an antidote to the ‘isolation [that] occurs because western culture, our individualistic narrative, the inward attention of our institutions and our professions, and the messages from our media all fragment us. We are broken into pieces’ (Block, 2008, p. 2). As Denning puts it, storytelling allows positive, hopeful change: ‘There’s an old Brazilian proverb that when you dream alone it’s just a dream, but when you dream together it’s already the beginning of a new reality’ (Denning, 2005, p. 68). However fanciful turning dreams into reality may sound (and as later chapters will suggest), without the optimism held in a story’s implicit vision, there is very little chance that alternative paths will change the current situation for many (Senge, 2006).

... history has much too say about contemporary society. It is a storehouse and repository of the experience, wisdom, follies and moral precepts which can and should provide the ‘wiring’ for a better world today. (Macintosh, 2002, p. 5)

It is hard, *today*, to view history as having fully included disabled people, because *reality* only reveals itself with the distortion of distance from contextual bias and through the misrepresentation of privilege of a present day lens. Disabled people’s history can be told as dark and murky affair (Oliver, 1990), with much shame linked to segregation, institutionalisation and sterilisation (Barton, 2005). Literally thousands have lost their lives fighting for visibility and global equality – a right to education, a right to work, a right to a life in community, and a right to a family life (Morris, 1995). Equally, the privilege that enabled the earlier disability movement’s knowers to tell of their

experience and understanding of barriers, and to theorise about a social oppression akin to sexism, racism, or homophobia, was a positive step forward for the disability movement. However, while empowering for their tellers, these radical stories will have also contributed unwittingly to the further marginalisation of other individuals who could not be heard (Shakespeare, 2006). The past must be viewed in the historical context of society, with the understanding that privilege plays a part in who gets to author *history*. Even shared stories can silence certain authors, and single stories can invalidate the teller, so the *dis-story* is one authored by disabled people. Allies are those that tell this story, disabled or not, recognising where it began and by whom it was started. As with evidence-based knowledge, what matters is the blend of personal experience, working wisdom and research evidence that enables a truth with understanding, judgement and knowledge.

What characterised the birth of the disability movement was that voices came together across barriers imposed by segregation and rejection in a struggle to be heard. Men and women stepped forward to articulate a time, a context, circumstances and organisation that stood in the way of their empowerment. They spoke of their interests, as a community and an association, a network. They spoke of how research contributed to their feelings of disempowerment (Oliver, 2007), because it saw *them* as a problem to be solved. Sadly, today is déjà vu all over again: ‘40 years on, much of what the UPIAS [the Union of Physically Impaired Against Segregation] warned against has come to be, entrenching rather than overcoming dependency... mired in austerity, the political and philosophical division between those focused on income security and those pursuing inclusion is, sadly, alive and well’ (Crowther, 2014). Survivors speak of treatment both cruel and dehumanising:

“Your head is all full of broken bottles once you realise that you don’t belong.” [the hospital] was less of a mental institution than a warehouse, where those deemed society’s misfits were deposited... (Brown, 2013)

This was further backed by economic pressures, the positive attractiveness of progress. Why bother to change society when news stories argue for prenatal testing to prevent the birth of severely

impaired children, such as those who are blind, have Downs' syndrome, are autistic or those with severe "mental" difficulties? Death is deemed to be in the public interest. Still, advertisements that endorse charities that care and cure for people with specific impairments appear regularly on our screens and radios; these are usually in highly emotive design and language. Little regard is given to non-respectful language that perpetuates ideas of dependency, cost, need and shame: survivor, brave, tragic, courageous, carer, sufferers and victims. Few stories carry messages that contradict the social oppression or discrimination that leads to human rights abuse on our very doorstep. In films, soaps and books, disabled people tend to be either nasty characters or brave and courageous individuals who lose their place in their community or their sexual power. They then disappear, die or get better in the end. No-one just exists with their impairment. Non-disabled actors are assured Oscars and fame by playing a disabled character.

While the movement is hard to pin down, Disability Rights UK provides a good summary of the interest to which Disabled and Deaf People's Organisations subscribe. They will not represent every individual's choice, but at least puts the wishes of the disabled population in positive terms.

1. To mobilise disabled people's leadership and control

We plan leadership programmes run by and for disabled people. These build on our award winning leadership programmes that have shown the strengths that disabled people often bring to community based, or work-based, leadership roles: resilience, empathy, problem solving, interpersonal skills and much more

2. To achieve independent living in practice

We plan to test new approaches to personal budgets and user-led commissioning, to increase real control for disabled people over our support; to support better and safer reporting of hate crime; and to influence government policy on health and social care

3. To break the link between disability and poverty

Our anti-poverty approach is based on 3 planks – skills/education, employment and a fair benefits system. We will disseminate widely our information written by and for disabled people, work to improve opportunities - including for apprenticeships – and influence government policy

4. To put disability equality and human rights into practice across society

We will work with partners to put disability at the heart of equality and human rights policy.

(Disability Rights UK)

Disabled people and allies can speak clearly within any conversation on these themes. It does not mean other concerns are not important to people, but it allows a ways of switching between personal, organisational and global perspectives. The key word is 'and' rather than 'or', the perspectives are equally important, not hierarchically ordered, as will be explored accountability comes with a multi-dimensional view encompassing three/four layers of oppression.

Where exchange and connection are seen as the sustaining elements of human flourishing, an assumed idea of illness rarefies the complexity of disability as a three-tiered personal, cultural and societal oppression. Furthermore, the lack of an adequate definition has been critical, often harmful, as disabled people have been both shunned and blamed for their imperfections. As researcher in disability and policy Jenny Morris puts it:

The social model enables us to place our experience of disadvantage in the context of how individuals, organisations and institutions interact with us. The medical model places the focus entirely on how we experience our impairments. (Morris, 2013)

To sum up, common misconception is that disability equates to illness, deficit, or failing to disability (Campbell & Oliver, 1996; Shakespeare, 2006; Chapman, 2011; Goodley, 2014; Slorach, 2015). In other words, the difference of the person equates to identity and the impairment is a differentiator. Sadly, this is to misinterpret the situation that disabled people face, as many see their impairment as the *least* problematic factor, and the cultural barriers and societal attitudes as enormously *more* problematic (Oliver, 1990; Campbell & Oliver, 1996; Shakespeare, 2006; Slorach, 2016). Not being able to access a building is a problem: however, being denied right of education, housing and healthcare **because** of a perceived human failing has far greater implications

on wellbeing for a lifetime. As the community organising literature states in terms of social justice the words ‘interest’ and ‘issue’ denote very different ways of articulating an entitlement to which organisations and institutions are accountable (Craig *et al*, 2011).

Creating space for disabled people’s voices is not an original idea: feminist research has previously highlighted silencing (Morris, 1995). More recently Beauchamp-Pryor (2012) makes the distinction between absent and unheard regarding voices within dominant narratives, while Goodley specifies the voice of those with impairments as storied to bring ‘in the accounts of people with ‘learning difficulties’ that a challenging epistemology that takes seriously the sociological core of living with the label impairment in, and as, personal and social narratives... As Aspis suggests, people with ‘learning difficulties are consistently underwritten (2001, p. 211). Storytellers may tell a different tale when representing another’s experience, but emancipatory research requires supporting people to learn and to grow from their own experience - to acknowledge the difficult truths, particularly where circumstances are hard (Freire, 1970).

4.5 Stepping forward

The narratives of injustice highlighted exemplify how the epistemic injustice imposed on the disabled population silence disabled authors, as its orthotoxic nature distorts their interests. In texts about human rights, as in storytelling more widely, accounts presented as blended knowledge are often subject to voids, and conversations about human rights are silenced by conversations about growth. Together the five tiers help explain the extent to which ableism has always been part of society, but without a language to articulate them specifically ableism has not existed as a cost. Therefore, not treating the disabled population fairly remained an unacknowledged reality to which all but a few organisations failed to be accountable (Hines, 1988). It is the absence that has let an ignorance based on false memory, because unlike ‘explicitly held knowledge, where you can be

reflective and picky about what you believe, associative memory seems to be fairly indiscriminate in what it takes on board' (Fine, 2010, loc 388).

A more complex and layered view of disabled people's position throughout history is needed to remedy this. One drawing on lived experience, working wisdom and research evidence, has been reduced to assumptions based on a limited world-view. It is the whole story, as we will see, that is critical to an articulation of accountability supporting human rights. One that is relevant to a legitimacy that is defined as a duty to communicate the impact of an organisation's activity on a specific group within society (Gray, Adams, & Owen, 2014). Because legitimacy needs to mean going beyond the financial reports to stakeholders as organisations to the wider responsibilities that lie beyond monetary concerns. Accounts need to say more about inequality and discrimination as it is experienced across the world. Accounting needs to be an equitable practice, 'a political and social process in that makes choices about the world; emphasises certain things and privileges or ignores others, thereby creating, to all intents and purposes, its own social reality ' (Gray, Adams, & Owen, 2014, p. 4).

Chapter five will present a framework, a web of accountabilities, which can be viewed as way of engaging in different dialogues to reach a degree commitment to upholding the interests of disabled people. Through language policy lens, the chapter explores different perspectives on human rights that stand in opposition to the narratives of injustice in this chapter, and are put forward as a qualitative articulation of a life led to its fullest [articles 8, 25, and 27].

The larger culture is always applying pressure, and unless we're willing to push back and fight for what we believe in, the default becomes a state of scarcity. We're called to "dare greatly" every time we make choices that challenge the social climate of scarcity. (Brown, 2012, p. 29)

Chapter Five

Accountabilities: a human rights imperative

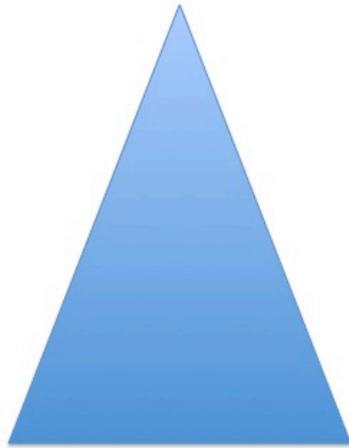
5.1 An idealised frame for dialogue

One conversation is not enough to change the narratives of injustice laid out as five tiers in the last chapter. Divergent conversation will be needed to insure that ableism is challenged on its many levels. What could such conversations look like? As an idealised frame, the five facets of the web of accountabilities motif presented below provides the shape beyond which conversations could be broadened, extending organisational storytelling to one that holds its legitimacy with the disabled people's movement. Conversations here are understood in terms of dialogic action, which are terms used in Sennet's work on community empowerment, not just words in an exchange but as intentional dialogue that seeks contrast – not agreement or compromise.

Though no shared agreements may be reached, through the process of exchange people may become more aware of their own views and expand their understanding of one another' (Sennet, 2003, loc. 56).

Legitimacy is extended with intention to address global, national, working, group and individuals narratives, by extending divergence at odds with each character of injustice (Mouffe, 2014). These conversation are laid out in a star shaped web, putting shape to a conceptualisation of accountability as a storytelling that extends to challenge, or mediate, orthotoxic culture more widely. This extension of accountability seeks to encompass a deeper engagement towards legitimacy, by making disabled people's interest more explicit. The area within the web indicates where dialogic action expands to adopt divergent narratives blending them to create a more nuanced storytelling with power to counter silencing in chapter 2. The web of accountabilities, as an idealised frame offers a way to critically unpack accounts, giving an understanding that must become more sophisticated, by drawing on developments both within the accounting literature and beyond (Tilling, 2004).

Top-down conversation



Centre-out conversation

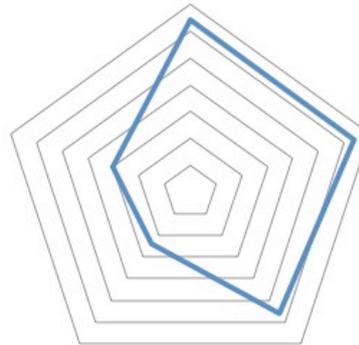


Figure 5.1 : organisational representation

As Helgesen (2005) suggests, the web shape itself [on right in fig 5.1] is a useful way of describing the direction of flow of power within lines of communication. The web shape avoids the idea of rank so often implied by a triangle. What is at the top of the triangle is assumed to have power over others, in turn suggesting a top-down hierarchy within an organisation. Replacing triangular shapes with the flat lines of a web changes the assumed layers of command, giving them a suggested in/outward direction allowing people at the centre to talk more directly with those at the edges (Helgesen, 2005). The image of the web of accountabilities has no numbers, because the shape's purpose is to visually represent the direction of conversation. Chiefly, it helped demonstrate that accountabilities could be represented as more than a financial continuum, as it introduces the possibility of many dimensions adding nuance. The shape was used to show meanings that are often complex, and therefore left out of the arguments used to defend legitimacy.

Following on from the last chapter, accountabilities are laid out as a multi-stranded conversation, purposeful dialogues along five themes, through which organisations can qualify its participation.

The themes of political, community, innovative, and civic add to a financial focus, in ways that map a manifesto for legitimacy. The web's multi-stranded scale provides a number of ways in which an organisation could add storytelling in order to reach better empowerment through an equity imperative. Dialogue is used here in the sense of craft, rather than technicality; the participants are encouraged not to seek a middle ground, but through 'the process of exchange people may become more aware of their own views and expand their understanding of one another' (Sennet, 2003, loc. 372). Dialogues are broadened through stretching narratives in human rights debates, adding together sometimes contradictory ideas and seeking new and alternative conversations that open fresh lines of thinking, rather than polarising debates along continuums or closing in on one idea (Sennet, 2003).

The illustrations map trust in the self-representation of disabled people, a progress towards more empowering culture along five axes (Fig 5.2). Each axis – political, community, innovative, financial and civic – represents the frequency with which the interests of the disabled population are mentioned within an organisation. The resulting shape provides a qualitative measure to contrast organisation or institutional culture. The contrasting shapes will be used later in the exploration of why ReShape's culture is exceptional, and underpins the theorisation about the relative possibilities of anti-ableist intent in chapter eight. As figure 5.2 depicts, each line in the web provides a sliding scale, thus allowing a comparative analysis to other organisations. Pleasingly, the web also reprises earlier ideas on trust said to be 'at the centre of a whole **web** of concepts' (Hawley, 2012, p. 6).

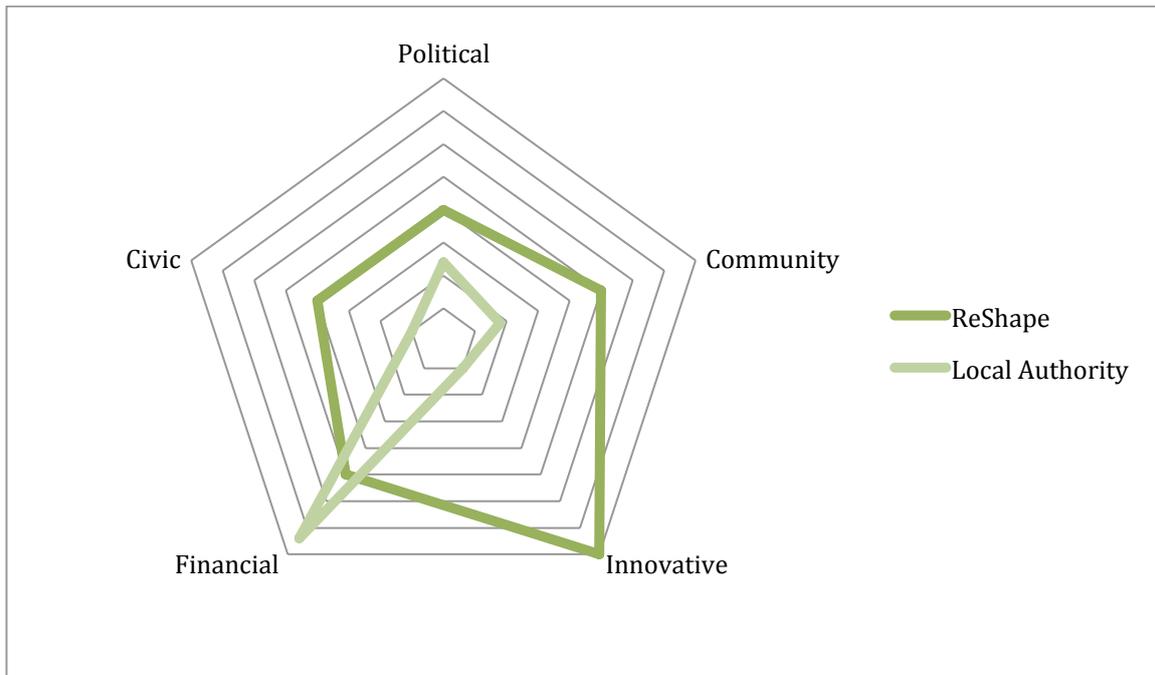


Figure 5.2 Web of accountabilities

This multi-stranded representation qualifies development of ideas along multiple axes, which help avoid the dualities associated with the view of accountability as a product of either good or bad culture (Roberts, 1991; Sinclair, 1995; Koppell, 2005). As I saw it, the wider the star, the greater the chance of human rights to be articulated fully! For in its multidimensional view, the framework speaks of movement towards a wider vision in a far more fluid and less binary articulation of progress (Gallhofer & Haslam, 2011). As Handy (2015) explains, innovation stems from a paradigm shift away from existing direction, more akin to a craft because it challenges existing narratives rather than securing justification for incremental adjustment within existing ones (Sennet, 2003). This requires new tales to be explored and radical shifts, needing ‘imagination, intuition and instinct more than rational analysis’ (*Ibid*, 2015, loc 267). Furthermore, the shape suggests a staggered movement suggestive of the waves described by Hawken’s (2007) multiple culture shifts some relatively shallow curves, and others the rapid sequence of waves formed by the incremental shifts of practice.

5.2 A human rights imperative

It is the rejection of the assumption of fairness that flips financial rectitude into the domain of a craft that could reach further towards a human rights imperative. As Hines articulates, ‘It seems to me, that your power is a hidden power, because people only think of you as communicating reality, but in communicating reality, you construct reality’ (Hines, 1988, p.253). As we have seen, ableism remains invisible where people do not recognise its power, or fails to speak its name, within institutional or societal debates. Because, where accountability is held in trust in the telling of an organisation’s activity, it appears this barely serves as a minimum nod to compliance towards the disabled population. “Everybody is basically the same” expresses a neutrality-seeking view of the world’ (Sennet, 2003, loc 179); an oppressive view that avoids the divergent ideas of a human rights crisis and therefore erases the nuances of the narratives of injustice outlined in the last chapter. For this reason the narratives that address equity need to have within them a language that speaks of **imperative** – not duty, because emancipation needs to be held within a central position any dialogue seeking to secure it. Equity needs to be viewed as an intrinsic part of purpose and vision, not a bolt-on or kindly addition. An imperative equity is critical to a definition of accountabilities as it adds to the understanding of the difference between accommodation to present day inequality and the need to address cultural and societal structures and systems for greater justice in the future. Therefore, defining equity as different from equality means fully acknowledging the distortions leading to mis-representation discussed previously. Sometimes expressed as *pragmatic equality*, equity can be defined as dealing with the specific *extra* unfairness imposed on the disabled population *in addition* to the inequality that affects the whole population (Wolff, 2011). Being able to address inequality in ways that go beyond duty, in operational ways of working, is fundamental to addressing the scale of impact, and includes an ‘intergenerational concern: acknowledging the impact our decisions today will have on future generations. Some writers refer to these future people we have not met yet as “our neighbors in time’ (Robertson, 2014, p. 6). An definition of

accountability that holds legitimacy needs to recognise a duty to provide an account, and not necessarily a financial one, within a story telling of those actions to which the organisation may be held responsible (Deegan & Unerman, 2011, p. 351).

Adding divergent narratives need not be seen as opposing more qualitative financial measures. But the specific addition of narratives disrupting the injustice identified may help to challenge culture through a storytelling that is anti-ableist at its heart. Legitimacy starts with (but needs to go beyond) the individual voices of disabled people in a self-representative tale – a dis-story, as outlined in section 4.4. Legitimacy needs establishing and extending in many organisations (Tilling, 2004), because justification has involved a denial or rebuttal to the voices of disabled people. Accountability will rest on changing how disabled people are perceived by acknowledging how their historical position in society has reinforced their silencing, in order to be retold in the future – or re-counted – without distortion. As Kamuf puts it, an ability to account - *accounterability* – involves intentionally highlighting group interests, and those chosen ideas that secure the precarious entitlement of those customarily silenced. Thus, ‘accountability might very well be used to mean narratability, that is, the possibility of accounting for something through narrative’ (Kamuf, 2007, pp. 251-252). Adding to organisations’ reporting through a narrative based on evidence-based knowledge could be a proactive way to elevate its strategy beyond compliance. A narrative supporting equity needs to be conceived as having the potential to foster long-term change with emancipatory vision, such as a defined aim to secure increasing justice for the disabled population.

Human rights are central to emancipation, as the Scottish Human Rights Commission states:

A human rights based approach empowers people to know and claim their rights. It increases the ability of organisations, public bodies and businesses to fulfil their human rights obligations. It also creates solid accountability so people can seek remedies when their rights are violated.

The **PANEL** principles are one way of breaking down what a human rights based approach means in practice.

PANEL stands for **P**articipation, **A**ccountability, **N**on-Discrimination and **E**quality, **E**mpowerment and **L**egality. (Scottish Human Rights Commission, 2018)

A human rights approach

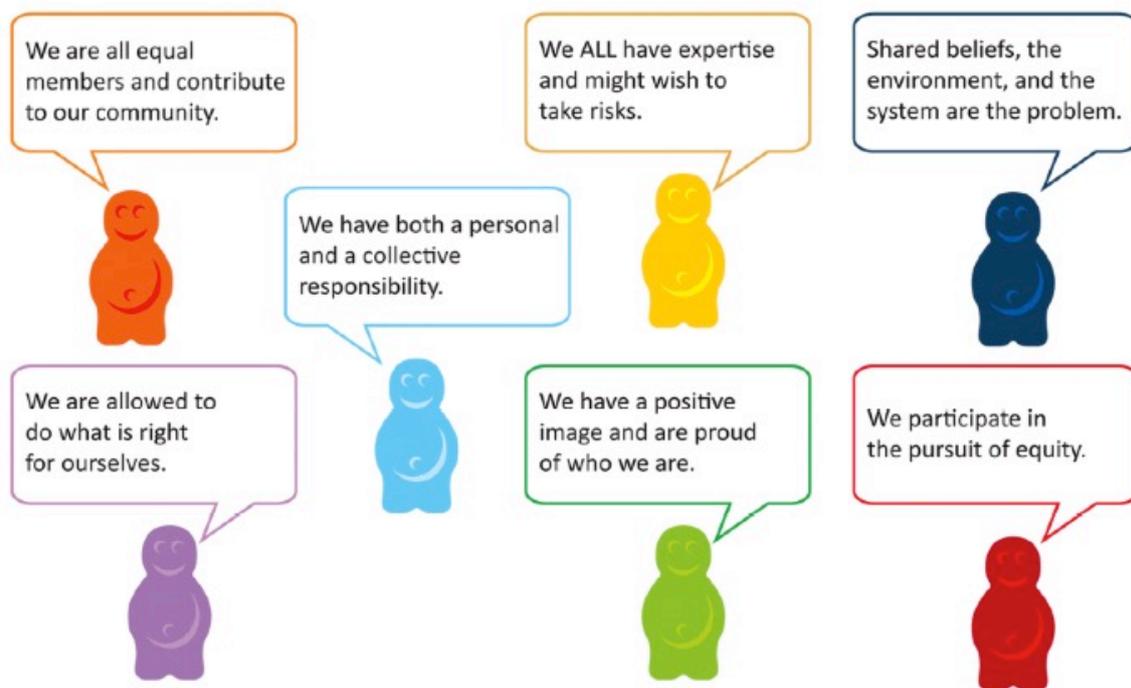


Figure 5.3 human rights and panel principles

Worryingly though, as Sennet (2003) explains, when people are viewed through a consumer lens, it affects how they are perceived. Viewed as consumers, not citizens, disabled people's rights to support are seen through a market lens, not a civic one. This means their needs are seen as the result of a paid service – not an entitlement to wellbeing, but part of a marketable exchange. This in turn means services can be monetised. Unfortunately, in this articulation they are perceived in a hierarchy, with those more costly often seen as less effective. In what becomes a transaction,

elements that define trust such as reliability, sensitivity, responsiveness and humour cease to have currency. Control ends up in the hands of the provider of service rather than the person in receipt of it, who is now framed as customer. Entitlement shifts away from view, as people are 'rendered spectators of their own needs, ... experienced that peculiar lack of respect that consists of not being seen, not being accounted for as full human beings' (Sennet, 2003, p. 13). Accountability is often seen as 'a duty to provide information to those who have a right to it' (Gray, Adams, & Owen, 2014, p. 7) and its financial narrative is often equated to a standard of compliance in terms of cost efficiency.

However, in early work on accountability, Roberts (1991) proposed that hierarchical articulations re/produce the thinking associated with consumerist assumptions, narrowing a human rights agenda to what can be paid for. In contrast, a socialising form of practice whose focus is on interdependence has both moral and strategic dimensions that could broaden notions of accountability, encompassing many aspects that together would inform an emancipatory vision. A socialising accountability in conversations that include both civic and community interests would be far more in tune with the interdependencies of a global view and would embrace the many values not recognised by markets. The idea of shared interest and the communal and relational determinants of wellbeing would strengthen the emancipatory focus of multiple scales – accountabilities (Gallhofer, Haslam, Monk, & Roberts, 2006). Articulating what harms is crucial where injustice beyond the organisational levels add pressure to the problems experienced at personal and group levels (Speth, 2008). Intertangled systems, whilst seemingly beyond our perception or control, are still realities for organisation, as Alastair Pringle, the national director of the Equality and Human Rights Commission has stated: "The consequences of inequality, of exclusion, and of dependence for disabled people are all too evident...While we've seen greater cultural understanding and acceptance of disabled people's rights, these positive changes are

masking increased social isolation for many disabled people as our society and economic life undergoes significant structural changes' (Naysmith, 2015).

Webs of accountabilities, as a proposed ideal framework, moves away from notions of right or wrong to define accountability more as a 'cherished concept, sought after but elusive... accountability is subjectively constructed and changes with context' (Sinclair, 1995, p. 219). Also, they merge Koppel's (2005) multiple dimensions of transparency, liability, controllability, responsibility, and responsiveness with Sinclair's five forms of political, public, managerial, professional and personal dialogue (Sinclair, 1995), giving the frame direction or vision, with the human rights PANEL principles also underpinning the exploration to come. Thus, the way accountability is defined influences the narrative and texts within cultural contexts; because accountability will mean different things to different people (Sinclair, 1995).



Figure 5.4 The chameleon of accountability (Sinclair, 1995)

Suggested by Sinclair's writings, and simplistic in many ways, the idea of a chameleon serves well as a metaphor for accountability at this point [see fig. 5.4]. Because, as an animal that can change its colours to represent its surroundings, as the picture illustrates the beastie still manages to clearly

display team colours without changing itself radically. Equally, an organisation wishing to represent its human rights imperative, can choose to state the interests of the disabled population within its accounts by making them explicit within its storytelling, thereby still keeping its existing integrity and shape. With this in mind, the five sub-section within the next section explore each axis of the web of accountabilities in turn, highlighting the characteristics dialogic action in ways that hold disabled people's interests at their heart.

5.3 Web of accountabilities

The web of accountabilities integrates the ideas on power and authority discussed above, in a shape that helps show time given to tell an organisation's story with the adjustment of evidence-based knowledge. It shows an account *with* or in response *to* the interests of disabled people outlined in section 4.4. The facets of political, community, innovative, financial and civic accountability, respond to the inequality, polarisation, discrimination, disadvantage and individualisation of disability as a problem. Each direction help qualify time spent talking about ways to move away from narratives that harm. Thus, the following sections provide a different quality of storytelling, to help extend conversations in ways that make culture more accountable. From an emancipatory perspective, authors talk of alignment rather than a choice between the ends of a continuum, and in common parlance accountability is about being responsible for action (Gallhofer & Haslam, 2011). Using forms of accountability relating directly to human rights gave me a rich and specific terminology with which to describe, analyse and theorise on organisational culture in later chapters. Sinclair also adds that there are two sorts of narratives of accountability, these are 'structural and a personal discourse' (Sinclair, 1995, p. 219). In the example of 5.5 below, I have sought to compare the characteristics of internal conversation at ReShape with that of the local authority, with the mapping informed by the language workers at ReShape used to describe that of their funders.

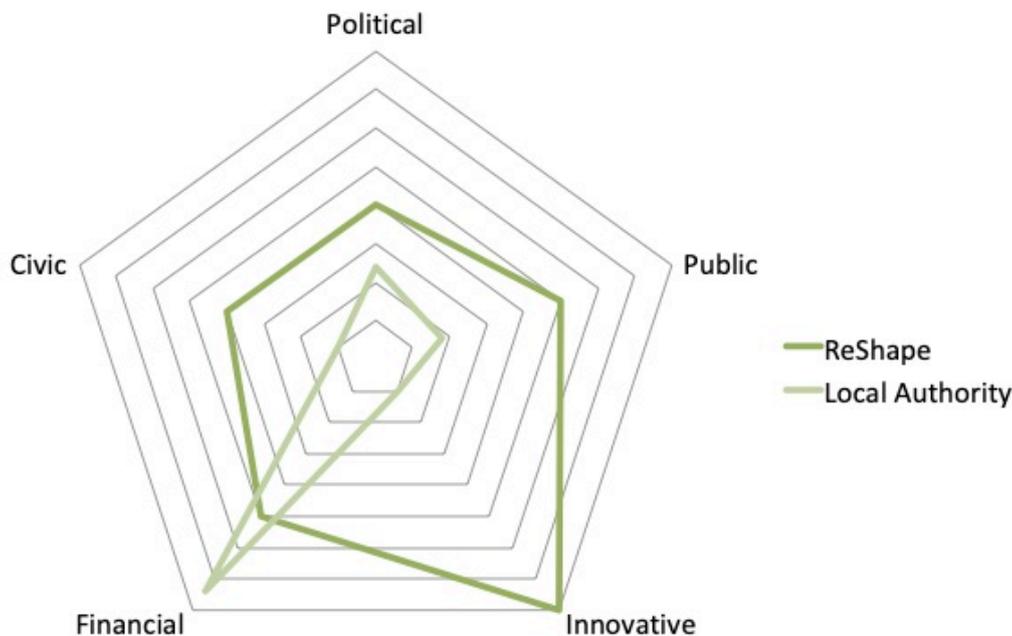


Figure 5.5 Web of accountabilities

5.3.1 Political dialogue

The characteristics of a political dialogue moves conversation away from issues of global division to view the articulation of inequality as a beneficial in the effort to address equality and thereby the group interest of the disabled population. As defined by Disabled and Deaf People's Organisations' [see p.142] shared interests include education, housing, employment, transport, relationships, leisure and respect. Political narratives are therefore those characterised by language that refers explicitly to these interests, without being political party-specific. This said, Labour (Labour Party, 2017) and the Green Party (The Green Party, 2017) have explicitly adopted the social model of disability in their manifestos. If more accountable terminology was evident in disability services, for example, wording would reflect the intent to speak of disabled people as activists with a number

of commonly held ideas. Ideas shared by the language within the feminist movement, for example, deals with interests such as reproductive rights, domestic violence, maternity leave, equal pay, women's suffrage, sexual harassment, and sexual violence, used to define the group culture - feminism. Language, thus can be viewed as tool to promote a political viewpoint, standing against discrimination, hate crime, and societal inequality, 'devices for promoting their causes... in terms of participation, representation and personal rights' (Shohamy, 2006, p. 135). A political dialogue creates new insights, as it negotiates what matters to a group such as the disabled population, with divergent storytelling emerging through opportunity for participation. It is the application of disabled people's authority to daily words that matter, because such intent 'also means that while it is expected that policy affects practice, it is also understood that practice has the power to affect policy' (Shohamy, 2006, p. 135). A political dialogue needs to acknowledge the geo-political perspective that a vast number of people are affected by ableism, as outlined in Chapter 4, and the denial of group interest globally will ultimately affect their lack of voice on local issues. Ignoring ableism that touches workers and users of services at a local level is to deny the scale of discrimination and inequality, because human rights 'violations are not accidents; they are not random in distribution or effect. Rights violations are, rather, symptoms of deeper pathologies of power and are linked intimately to the social conditions that so often determine who will suffer abuse and who will be shielded from harm' (Meekosha & Soldatic, 2011, p. 22). Thus, defining political dialogue from an equitable perspective means considering more than monetary gain or loss by clearly addressing the ableism within the inequality that threatens social justice for all (Wilkinson & Pickett, 2009; Marmot & Bell, 2012). While a measure of cost may be seen as the bottom line in operational terms, moral considerations and their long-term implications in strategic direction, can be understood as emancipatory within a systems approach (Mendonca & Kanungo, 1996; Senge, 2006). Focusing on more efficient ways of measuring hours in a job seems to miss the essence of what is asked for by the disabled population, and therefore falls short of addressing an

accountability for human rights. Using a human rights approach in conversation means talking about disabled people's entitlement in practice, policy and budgeting development. It will lead to a conversation about the impact of inequality **before** people are silenced, not least because 'there are many examples of policy intervention ... that have been well intended and rolled out into practice on the basis they seem plausible and unlikely to do any harm. This means that ineffective and even harmful initiatives can divert scarce resources away from effective ones' (Gorard, 2013, p. 5). Therefore, political dialogue needs to be built on evidence-based knowledge, in an authority that includes personal experience, practitioner wisdom and research evidence in equal measure (Section 2.3). Seeking a political dialogue is very different from adapting or domesticating interest to the ideology of an existing policy.

Legitimacy may be found in an ability to respond equitably, acknowledging the unequal advantage and power imbalance faced by the disabled population, in order to highlight the non-disabled population's advantage. A political dialogue becomes essential to having a voice in a policy, where it establishes and extends an ongoing conversation - a contract to be maintained. The self-representative language exemplifies an example of political dialogue here, used in this poster for Police Scotland's campaign against hate crime – Figure 5.6.

The characteristics of a political dialogue, are those which make the interests of marginalised

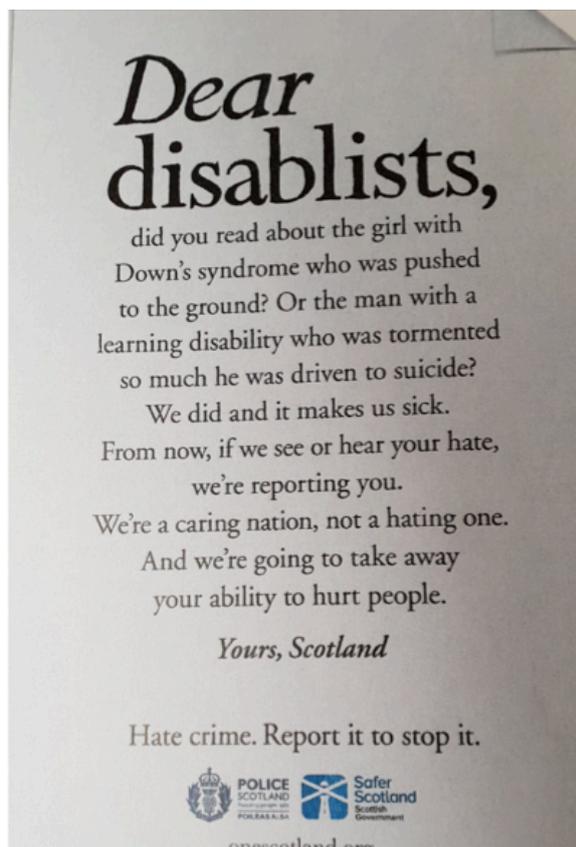


Figure 5.6 Police Scotland Hate Crime

groups public. The language allows for a subtle acknowledgement of identity, while focusing on the interest of the group. The distinction here, again in line with the social model of disability, is between private and public narratives with the former deserving the respect privacy provides. For example, an organisation can speak of its work to enhance the lives of people with mental illness (without having to talk of personal experience) by highlighting the specific barriers the group faces rather than the illness of individuals. This does not deny that individuals still need consideration: however the personal experience of individuals remains within the organisation's internal narrative. An example of political dialogue in which research evidence and personal experience had no voice was in the closure of the Independent Living Fund in England: it was a governmental decision that took a centrally administered fund and imposed it on local administrations. Defending the return to institutionalisation, the decision did not save money but imposed conditions that violated human rights. It also incurred a price for loss of human dignity, and one exemplified again by local authorities – in and beyond the home – on cost grounds (Greig, 2016; Series, 2017). As Scarlet (2015) explains, control is often forgotten in favour of narratives stating one-dimensional financial or procedural logic. Human rights were at the heart of the Independent Living Fund that promoted a story of people's right to homes while paying less for a more understanding way to support for people with severe impairments. Unfortunately, the decision was ultimately rejected on ideological grounds despite their effective success in ensuring the human rights of disabled people were met.

An emphasis on global matters in exchanges and documents, offering acknowledgement to the narratives of injustice outlined in section 4.3.1, adds economic inequality to financial matters in a political way, as the World Bank states:

The conversation needs to change. We need to focus on the structural issues of inequality—economic inequality, political inequality, and social inequality... Why is it that tens of millions are without food, medicine, education, or a *political voice*? *The realities go far deeper than just being poor.* (Emphasis added Rist *et al*, 2016)

Not usually prone to emotional statements, these words have a strong and expressive tone, they come across as a directive – not a mere wish. The focus referred to would need to be further qualified to be specific to the disabled population, adding an anti-ableist intent to wider narratives to avoid the power money has gained in political spheres (Thompson, 2007). Legitimacy built on extending conversation to integrate further the global, strategic and moral dimensions of sustainable development would strengthen accountability over time.

5.3.2 Community dialogue

Extending accountability by addressing the lack of nuance in more localised debates between nations also addresses disabled people's wellbeing within that of a entire population. A community dialogue thus, provides a subtly different narrative to the political one articulated above. I have used the community literature, also known as community organising, to articulate its cultural characteristics (Block, 2008; Diers, 2004; McKnight & Block, 2010; Minkler, 2012). Expanding an organisation's conversation to speak of matters of local interest, e.g. speaking to a neighbouring firm about plastic use, adds an outward-facing dimension to an organisation's accountability. I looked for a language guided by the ideas and theory relevant to practice development and the experience of its workers in that field (Montgomery, 2008). A community dialogue serves an identifiable purpose here, in that it helps to secure the shared understanding of a group. A community dialogue is a tangible conversation where people exchange information: it comprises ideas they will then draw upon to articulate their own knowledge. In terms of the injustice by which disabled people are disadvantaged, ableism, the words used became more prominent across the media and in research literature as the study progressed, possibly because resistance grew in a period marked by hardship under austerity policy (Wiggan, 2012; Beatty & Fothergill, 2013; Foley, 2017). In particular, resistance has grown where the defence of austerity measures have put those in receipt of welfare in a worse situation, since cuts impact materially on finance, work, infrastructure

and threaten the wellbeing of disabled people's lives, yet are beyond a consciousness represented in community dialogue (Goodley, Lawthom, & Runswick-Cole, 2014).

Minkler (2012) intentionally uses community 'interests' to avoid the words 'problems' or 'issues' to indicate what matters to local groups from a social justice perspective. However, because of social media they are more likely these days to take place across wider geographical boundaries, within more global networks. Examples might include access to woods, mental health campaigns, period poverty and tobacco-free zones. While the dimensions overlap and a political narrative may seem similar, from the ethnography perspective the language reflected conversations about local knowledge, with words that spoke of relationships beyond paid exchanges (McKnight & Block, 2010). Importantly, their quality was priceless as there are no alternatives available to buy, if they are not wholly free (Sandel, 2009).

A community dialogue – that is a personal narrative that is broadcast openly (for example on Twitter or Facebook) – emerged during the course of the study in ways it had not before the explosion of social media (Kozinets, 2015; Hine, 2015). While the narrative can be understood as an individual voice, it is not private, but a conversation about the stories told in society more broadly. The importance of a community dialogue is highlighted by Paul Hunt, Professor of Human Rights, assessment of UN envoy reporting on the extreme poverty witnessed having travelled the length and breadth of the United Kingdom: 'He is saying what the mainstream media, think-tanks, politicians and officials have – with rare exceptions – failed to say since 2008... austerity and poverty are among the most important human rights issues of our time. He is demonstrating that the austerity experienced by millions of people in Britain is in breach of the government's legally binding international social rights obligations. He is exposing the gaping hole at the heart of our national human rights system: its failure to explicitly recognise social rights' (Hunt, 2018).



Figure 5.7 Ableism in conversation on Twitter

Across public institutions more widely, developing a community dialogue that addresses ableism is rare because few have sought the Disability Equality Training enabling a sensitive and nuanced terminology. Building in the voice of disabled people to shared conversation needs to be intentional if it is to challenge years of harm. It is growing however, in the way the articulation of the Pink Tax has for feminists become a zone of gender negotiation, changing a business narrative, not only within shops but across many platforms. When ableism is articulated publically with energy and courage, within internal and localised narrative, it can to be turned outwards to the world. Viewed as responsiveness to an injustice growing in the public's mind, there is urgency in a conversation that could lead to meeting the demands of a substantial population (Koppell, 2005, p. 98). This suggests that for the sake of social justice and for accountability to be legitimate, conversation needs to be understood as having a role to play in creating space for disabled people's story - the articulation of their interest clearly acknowledged in all storytelling. It is worth restating the ideas of pioneering disability activists here who named the 'medical model' as the over-dominance of a

clinical frame for matters of disability) or put more simply, talk of illness in conversations where it is not typically spoken.

Making the implicit explicit is a verbal way of articulating hidden assumptions. A common story, for example, implicitly says that non-disabled workers deliver a ‘disability’ service to disabled people. Evidence suggests this idea is highly unlikely: it is more likely that a significant number of the workforce will be disabled – even if they do not identify or have hidden impairments - but issues of disclosure are complex and become confused in narratives found in policy and media (Khan, Korac-Kakabads, Skouloudis, & Dimopoulos, 2018). The ‘problem disabled people **have**’, has not yet been fully articulated as their interests in view of the ableism they **face**. Furthermore, as section 4.3.5 examines, placing the problem at personal level implicitly restates that its the individual’s problem.

An organisation seeking to strengthen its accountability by adding to its community dialogue will need to look beyond its own walls to find a voice of a recognised group then identifiable within them. For example, Disabled People's Organisation’s hold an authority as the representatives of the disabled population from an organisational perspective. This means that Disabled People's Organisations need to be acknowledged as having a specific contribution to public debates, one that is generally campaigning and activist, articulating rights from a civil rights perspective. It is a voice directed beyond the boundaries of organisations, that may involve different groups of people, funders, and other organisations within any sector, an articulated responsiveness which ‘turns accountability outward rather than upward’ (Koppell, 2005, p.98). It is a recognisable public voice used on behalf of a network that disrupts the narratives of injustice, often used unwittingly by charities who seek to maintain funding, but often at the cost of misrepresenting disabled people in stereotypes soliciting pity (Crow, 2014). For some community dialogue is threatened where it is

justified by a business narrative, where disabled ‘people and those close to them are facing a newly defined form of marginalisation’ (Goodley, 2014, p. 20); equally if it is too political, it loses objectivity and nuance; if it is too academic, it loses relevance and accessibility’ (Shakespeare, 2015, loc 203). Viewed thus, a community dialogue accomplishes positive change for disabled people: the differentiator in a community dialogue is that the conversation enables an allied position. Because to be an ally requires the empathy that comes from reflexivity, a dialogue enabling others to view another persons’ experience as different from their own. However, due to the historical segregation imposed on disabled people as a group, invisibility has traditionally accentuated a marginalised status, leaving the group viewed in ways that are dehumanising.

5.3.3 Innovative dialogue

This section responds to the injustice outlined in section 4.3.3 that highlights misconceptions of disability within the workplace and institutions. Leadership literature helps articulate the language of innovative dialogue, which can be seen as a different telling by alternative voices, rather than just the same teller giving alternative account (Senge, 2006). Changing storytelling involves rethinking which groups hold power (Thompson, 2007), acknowledging structural and societal privilege, and speaking against it (Pease, 2013). Divergent narratives are key, as improvement does not lead to better; alternatives are required to find a different direction and create a new culture (Sergiovanni, 1985; Hargeaves, 2005; Fullan, 2011; Handy, 2015). A definition of leadership activity that views language as action, puts the choice of words used as a use of personal power and help further empower others. At one end a dialogue devoid of elements relating to governance lacks accountability in the way it frames vision to realise human rights as impossible. A ‘not yet’ response, on the other hand, takes the long view, dealing with visions that go beyond immediate accommodation, with ideas bigger than the solutions that stop at duty and a minimal engagement

with societal impact. At the other, the conversation starts with the ‘what ifs’ that could transform present circumstances to achieve global flourishing for all earth dwellers.

An innovative dialogue can be imagined as a deliberate move away from a duty to improve current working assumptions by exploring the circumstances that have led to crises, and re-imagining a way forward driven by a different vision. As section 4.3.3 highlights, in the context of work, learning within cultures that re-present toxic ideas in their arrangements, disabled people cannot be addressed equitably without a challenge to prevailing assumptions of ableism. Learning is at the heart of transformation, and requires a language that can articulate movement within culture. From defining new vision, to trying new ways of working and the mistakes they involve, there need to be words defining fluidity, hope and aspiration for better ways of working (Adams & Clarke, 2009). Capacity and learning extend possibility, as Senge states: ‘Through learning we re-perceive the world and our relationship to it. Through learning we extend our capacity to create, to be part of the generative process of life...[and a learning organisation is] an organization that is continually expanding its capacity to create its future’ (Senge, 2006, pp. 13-15). Within the field of educational leadership for example, John West-Burnham says that ‘the prevailing orthodoxy is not delivering effective[ly] ... on an equitable basis then the role of leadership has to be to question and challenge that orthodoxy. The more deeply embedded the orthodoxy the greater the need for transformational leaders’ (West-Burnham, 2009, p. 12). Examples of such leaders are described in section 6.1.3, as those who re-invent systems having identified elements of current institutionalisation that harm.

New ways of working can only emerge when deeply held assumptions are challenged, and because current practices have been built on the segregation and institutionalisation do little to further disabled people’s wishes, however more efficient they may become. Richard Rieser, Director of the consultancy, World of Inclusion, states that the buildings of the old asylums remained, all that

changed were the signs above the doors: poor houses, asylums, mental hospitals, became day centres. Therefore, conversations that disrupt institutional assumptions need to diverge from established ways of working, process and procedures. In many ways, the conventions within services have gained more importance than the people they serve (Greig, 2016; Series, 2017). An innovative dialogue therefore needs to aim to transform culture, exposing existing inequalities by addressing the power base found within the institutional mindsets and knowledge base.

It is not that adding the voice of disabled people will remove bias, but in adding a textual and responsive sensitivity to organisational context, the storytelling adds additional perspectives on a shared humanity (Whitburn & Goodley, 2019). As underpinned by a human rights approach: 'Being human is not a matter of imaginatively discounting the significance of the barriers that have been erected between us, but then leaving those barriers in place... If those people still have power over us or we over them, we are not yet engaging fully with what it means for us both to be human beings' (Phillips, 2015, loc 85). More crucially, an innovative dialogue is required as an alternative storytelling. Viewed as leadership activity, strategic conversation needs to be built on co-authoring, a type of shared narrative that reshapes organisational stories in ways which radically address the meaning of ableism for workers within services and people beyond its walls.

5.3.4 Financial dialogue

As outlined so far in this chapter, disabled people are disadvantaged by silence in the areas of inequality, community voice, and shortcomings in the articulation of leadership activity. To address section 4.3.4, poverty is now tackled through an exploration of financial dialogue. Wellbeing literature here helps articulate the missing elements of the more common conversations about money, by widening the narratives about costs to include issues of privilege and disadvantage.

As the Whitehall studies have suggested it is a nuance around need and control, emphasising choice over money, that is important to a dialogue seeking financial fairness from wellbeing standpoint (Huppert, Baylis, & Kevene, 2005; Marmott, 2015). It is not that wellbeing can be guaranteed by money, but not having enough to suffice basic needs can kill: it is a sense of control in present circumstance that is fundamental to the present happiness short-term that leads to wellbeing in the long term (Layard, 2005; Huppert, Baylis, & Kevene, 2005; Gilbert, 2006; Diener, 2008). For individuals within under-privileged groups, and disabled people specifically, it is lack of control vis-a-vis basic needs being met, coupled with the assumption that low cost can automatically ensure efficiency, that denies both fairness and dignity in the provision of services. Within a system where eligibility needs to be proved, there is much confusion over fair amount and equal share, and even those on benefits are drawn to the assumption that other disabled people are getting more than they deserve (Green, 2017). The extra cost incurred by living with impairment(s) is on average £570 a month, because the prices of transport, housing, employment, support services and assistive technology are higher for disabled people (Papworth Trust, 2018). Furthermore, disabled people are far more likely to run into health costs that are high and push them under the poverty line (Slorach, 2015). Reports appearing as I write highlight the cost of illness caused by poverty, stating research by the Independent Living Strategy Group, whose chair Baroness Jane Campbell states: “The financial impact of personal care neglect such as pressure sores, kidney infections or falls, as well as stress related illnesses, means finding extra resources for the NHS” (Disability Rights UK, 2018). Furthermore, from the wellbeing perspective, not having enough for high days and emergencies leads to the critical stress that threatens day-to-day health (Layard, 2005), thus lack of control imposed by limited option can seriously put people at risk of more and prolonged illness (Marmot & Bell, 2012).

Financial considerations have a critical impact on health, by not having our needs met through financial insecurity and lack of control, has a detrimental effect on resilience (Marmot & Bell, 2012). In a world where inequality already imposes harm on all populations and where disabled people endure further hardship and discrimination, human rights abuse can be understood as imposing added financial penalty on ideological grounds in addition to injustice. Philosophically, 'If the source of disability is 'the world' rather than 'the person' then intelligent social policy may well aim to change the world, rather than compensate the disabled person... Another way of thinking about it might be to say that a world that is (pragmatically) equal in respect of disability should contain the same degree of inequality between disabled people as there is between able-bodied [sic] people' (Wolff, 2011, pp. 153-154). Our feelings may need to be disrupted on this issue: as a society can we afford to make a marginalised group suffer, because our hearts are affected by stories that impact on our decision making when at a distance from those impacted? The right decision, as Gladwell puts it, may be counterintuitive, such as putting money into undesirable projects, because doing so serves society better than the fallout in the long-run (2009).

The distortion at group level that fuels the narrative of privilege explored in section 4.3.4, rests on false assumptions, exemplified by the recent focus on austerity measures, welfare reform and services cuts - a new face to an old problem (Hughes, 2015). Whether disabled people deserve the money spent on their lives within a consumerist society interrupts an accountability based on a right to wellbeing. Ironically, institutionalisation was enabled by the economics of industrialisation, most noticeably in countries that sold and bought human capital in the form of wages, and where the very rich could afford the creation of workhouses and poorhouses to house the worthy poor (Oliver, 1990; Slorach, 2016; Goodley, 2018). The legacy of the benefactor/beneficiary relationship persists, demonstrated in welfare payments often covering no more than basic need (Equality and Human Rights Commission, 2018) and revealed in the increasingly low Direct Payments replacing already

low Self-Directed Support, in budget cuts driven by austerity policies (Manji, 2018). For those in decision-making positions, being unaware of this unfortunate history makes legitimacy vis-à-vis the disabled population less clear, as cuts driven by the availability of cheaper services are imposed irrespective of the characteristics of the support they provide (Series, 2017).

It seems critical to accountability to acknowledge this history of segregation, because its legacy in issues of welfare budgeting does little to disrupt the entrenched narratives and injustice of group privilege regarding cost. With the monetisation of care commonly understood as the notion of pounds-per-hour, cost has become a zone of financial tension synonymous with the negative impact of a market narrative similar to Sinclair's articulation of managerial accountability (1995). Can accountability be held by an organisation funded by government? Particularly if the group it serves is a disadvantaged one, without the organisation expressing clearly its stand against the narratives that ultimately lead to poor decision making. In other words, where is the answerability or responsiveness (Koppell, 2005), without the dialogic action required to secure understanding in the difference between need and want? As defined by privilege and outlined in section 4.2.3, having a notion of scale means stating that small amounts of money, say £5, can have huge impact on those who have the least. Financial hardship, does not deter the ill-deserving, it is life-threatening to those oppressed by poverty (Runswick-Cole, Goodley, & Lawthorn, 2014) As a participant in a training session ONCE commented: "words have a nuanced meaning. Saying you are starving at lunchtime has a different meaning for individuals who cannot afford the food they need".

With this perspective established, viewing a service that is within its budget as cost-efficient may deny its lack of accountability, particularly if it is not preventing harm by addressing activity that adds pain to the people it serves (Speth, 2008). A service that answers a call to legitimacy is one that enhances the lives of those in receipt of it: one that may not be replaced by support is merely

judged as being cheaper (Giddens, 2013). Empowerment has no substitute as legitimacy is quite literally irreplaceable, because where services are cheaper but have a negative impact on the people they serve, the cost is damaging (Crowther, 2014). The cost of ignoring relationships is far greater than can be measured in a timeframe, as it is the investment that strengthens autonomy over time. When cuts also deny rights, established relationships for example, there is no alternative option, as there is no means of replacing what is lost – even *with* money. It is the priceless element of care that needs to factor in any measurement of quality – the investment in emotional labour (Hochschild, 2012) – the time to know and effort to change. The price of the breakdown includes personal pain in a system already ill equipped to measure the real worth of good care.

For those organisations that straddle the boundaries of government where financial accountability is driven by the business narrative of cost, the distortion in storytelling fails to convey that poverty, and the way disabled people are viewed as costly, is a matter of *belonging*. An assumption hidden below the way ableist disadvantage is named rarely articulates the non-disabled privilege to include or exclude disabled people. Language, exemplified by the common usage of able-bodied, to define non-disabled people focuses on being *able*, which poorly conveys that disability is about the unearned cost - a privilege for those not disadvantaged by ableism. The cost is not the differentiator but the ability to voice financial considerations more fully to voice a commitment to the wellbeing that ultimately supports emancipation.

5.3.5 Civic dialogue

As outward-facing action, civic dialogue is possibly the hardest conversation to expand. Yet the outcomes of civic dialogue may be seen as emergent storylines that depict the imperatives that push society forward, and therefore answer those of the Sustainable Development Goals. Civic dialogue seeks to articulate an understanding of disabled people as community members. As discussed in

section 4.3.5, disabled individuals are often framed as good or bad, deserving or not, by a distorted view that makes acceptance conditional on likability. Balancing the right of individuals to tell their unique stories, often requires mediating that storytelling through the other political, public, innovative and financial conversations discussed earlier. In issues of welfare policy, for example, an unchallenged belief in stereotypes often puts blame on those disadvantaged by inequality because of writers' prejudice. Particularly where policy 'documents marginalize the structural aspects of persistent unemployment and poverty by transforming these into individual pathologies of benefit dependency and worklessness' (Wiggin, 2012, p. 383). Addressing ableism in language, and its contribution to disadvantage, enables a more proactive intention within the texts of the workplace, so they do more than less-harm to those citizens who have less of life's advantages to start with (Pease, 2013)

As Sinclair (1995) suggests, the use of structural framing in personal narratives is useful to name ableism explicitly. Because empowerment is often about negotiating a personal story within wider narratives and therefore articulates the rights of the whole group. Empowerment here means helping others to believe in their ability to flourish, by fostering a culture that values change and success (Fullan 2007, Block and McKnight 2010). For the worker straddling market and government boundaries, accountability is sought by the articulation of stepping out of their business into often personal spaces. Unless framed by a civic narrative, a paid service can easily sound oppressive in its denial of what is personal, confidential and filled with ambiguity. Furthermore, the characteristics of language need to state an emotional content that is usually dismissed as subjectivity in workplace culture (Shakespeare, 2006). Holding the civic voice while protecting the private one, in the glare of the consumerist and individualist narratives that proliferate beyond the organisation, is hard.

The civic nature of accountability is particularly difficult to extend in organisational dialogue where pain has become banal; we are seeing a rising tolerance in society of the unhappiness and pain of certain groups, that lets an absence of shared outrage to injustice in countries where riches grow yet poverty affects more of the population, year on year (Dejours, 2014). We are missing a language which expresses these dynamics, making it hard to articulate the oppression disabled people face without being oppressive or offering an immediate solution. It is similar to calling out sexism, without pointing the finger at men or telling of women as victims, but highlighting feminist ideas that empower without the possibility of an instant remedy to its systemic nature (Pease, 2013).

In the extension of civic dialogue, dialogic action may help counter the potential harm of conversations overly influenced bias in cultural and societal narratives. The language of citizenship may help restore individuality in the sense of a more typical shared humanity lost in narratives that impose likeability linked to the stereotypes associated with disabled storytellers, as identified in section 4.3.5. Furthermore, a civic dialogue that aims to secure willingness in creating more equitable cultures (Fullan, 2011), by opening conversations of a more strategic nature, that are forward thinking and positive about a co-created vision, will hold the possibility of a culture in which people want to belong (Block, *Community: The structure of belonging*, 2008). Empowerment here means helping others to believe in their ability to flourish, to create change and to achieve success (Lawson 2003, Block and McKnight 2010, Fullan 2011).

As Sinclair (1995) suggests, the ability to differentiate between structural and personal of narratives to lever change is important. Because care is personal, confidential and filled with ambiguity, so the characteristics of language need to see the emotional content usually attributed to subjectivity as worthy of measures (Shakespeare, 2006). More importantly, a civic dialogue may help question the absence of disabled storytellers in a story widely told, highlighting the voice of disabled people as

they become more visible in society. Viewed thus, civic dialogue can be used to further the interest of disabled people by helping to articulate a distinction between ‘doing it right’ and ‘doing the right thing’, with the right thing bringing forth a preferred state for those on the planet in the long-term (West-Burnham, 1988). Conversations will involve questioning issues of unchallenged inequality linked to belief, talent, luck and faith. In this sense, defining one’s principles involves understanding much broader theories of ethical concepts (West-Burnham, 2009). As a direction for accountability, civic dialogue needs to say more than the minimum standards of effective practice, the vision needs to follow a moral and ethical dimension of responsible business, where the operational and strategic come together in congruence (Whittington, 2001; Sergiovanni, 2005). A dialogue of civic intent may sound simplistic, but because it is grounded in a great depth of knowledge, it is like an iceberg, what is submerged has enormous volume.

5.4 Banking on hope and talking with courage

Drawing on the past five sections, an emerging articulation of accountability as a web shape permits a description of the different narratives that diverge from injustice, thus adding legitimacy in organisational storytelling. This suggests that accountability can move towards a more emancipatory ideal, one in which reporting tells fuller stories, because there are still too few words to adequately state these matters, and workers need to play bigger roles within society to convey their responsibility towards civil groups within it (McPhail & Walters, 2009). The complex and nuanced weave helps plot a notion of responsiveness to the tiers of harm disabled people face laid out in chapter four, by qualifying an ability to account in conversation. Together, the axes can be viewed as a robust articulation against inequality, discrimination and disadvantage. As an idealised framework, their opposition to how disabled people’s voices are ignored in the telling of ordinary stories, these new avenues of conversation could shape organisational accounts to tell society more than the presumed orthodoxy of numbers and rectitude of statistical measures.

Given their emotional tone, conversations are likely to require courage (Kline, 1999; Brown, 2012). Because when talking about injustice, speakers are likely to uncover the unfairness in their working practice, and they will need to deal with the anxiety that is unleashed when assumptions linked to habit are challenged (Schein, 2010). Internal language may clash with external ones, language needed to satisfy external relationships, as ‘an organization cannot concomitantly satisfy hierarchical superiors, behave consistently with all laws, norms, and obligations, and respond to the demands or needs of constituents’ (Koppell, 2005, p. 99). This technicality demanded by other organisations can tend towards instrumentality, which unfortunately strips dialogue of the very storytelling that articulates the commitment that supports alternative futures (Senge, 2006). More specifically, some technical language omits the descriptive detail around the complex interests within a human rights narrative. Courage is needed therefore to stay on track, despite opposition, and maintain a storytelling that articulates responsibility for self-direction, respect and dignity, in lives free from threat, pain or shame. The characteristics of each narrative are important, with some more mechanistic than others: the addition of feeling (whether passionate or caring), brings greater flexibility in the response to individual needs (Hochschild, 2012; Vosselman, 2016). Courage has been linked to a spiritual journey because such a dialogue challenges the existing landscape. By broadening individual mindscapes with the intention of achieving new realities, it must deviate from narratives of injustice to be effective (Sergiovanni, *Landscapes, mindscapes, and reflective practice in supervision*, 1985). Dialogic action calls for more than the minimum standards of good practice: it adds nuance to the moral and ethical dimensions of responsible business, where the operational and strategic come together in congruence.

5.4 Stepping forward

The web of accountabilities is an idealised frame that illustrates how diverse voices can be engaged in different types of conversation in order to help secure a commitment to vision of human rights for disabled people. The characteristics of each dialogue, also act to move away from the ableist ideas that hinder emancipatory movement. The web of accountabilities can viewed here as minimum terms, or essential standards. In addition to it, the vignettes in the next chapter are proof of existing culture, as snapshots of organisational life. The web serves as a map, setting direction for accounts of dialogue that is emancipatory: a multi-narrative qualification that reaches far beyond the legalistic measures of compliance (or least-harm) to address the specifics of injustice. Accountability is context driven, and is influenced differently in different places. In this way legitimacy can be understood as a committed response to accountability aiming for positive change for disadvantaged groups. Accountability here is more in line with leadership, direction and vision, to support human rights through wellbeing for every person (Chapman, 2011).

The next chapter moves on to storytelling. Rather than a prose, the vignette text is written to provide alternative views, with a number of sometimes contradicting truths, rather than a timed and linear sequence of organisational life. Vignettes have a research purpose of holding together interpretation, moral ambiguity and sensitivity regarding the norm (Finch, 1987). Together they provide different angles on a whole, rather than a full shape, a thick description qualifying the accountability held in the relationships within organisation and outside it. There can be no neutrality as traditionally understood: the account is interpretive not objective or subjective, as the judgement can be qualified but not removed (Agar, 1986).

Interlude

Thanks to ReShape, Jean has her own home. The nightmares continue, but thankfully not the humiliation. Those around her acknowledge the harm she has suffered. It is now far easier to get through the day, because the sensitive words that surround her interrupt those that haunt her. Positive attitudes help her think differently about the future. People know her story, understand her fears, and work with her to prepare for happier days. If she shouts or cries those close to her know why. They understand how the telling of her story is a unique tale, but that as one of many it also stands against a wider storytelling that rejects the truth of similar voices. In leaving the institution, Jean escaped the painful limbo of being trapped within pale green walls. She escaped being the victim of sadistic whims and a prisoner of a Victorian regime. The institutionalisation still imposed on so many. Decisions made to save money, despite the great costs that are justified by greed and envy.

The stories perform that uniquely human gift – carrying an idea from one mind to another in complexity and with emotion. Stories conquer death – tell a story about someone well and there he is, returned to life, laughing so hard with his arm around his brother that he can hardly stand.
(Gregory, 2011, Loc 60)

Part 3

Chapter Six

In the Field

“Where, after all, do universal human rights begin? In small places, close to home – so close and so small that they cannot be seen on any maps of the world” Eleanor Roosevelt

6.1 The visit: bathing the room in sunshine

In the next few pages I tell a story. It is a performance of sorts, because whilst the text is static, the reader as audience will interpret meanings from many more angles than the words alone (Shohamy, 2006). In this sense the following is a tango - not a solo piece but a shared experience, negotiated in a dialogue from which meaning and sense will emerge differently at every reading. I wanted the vignettes to feel alive, immediate and true to the organisation’s culture. I aim to show that when tuning in with sensitivity and turning up the volume on a selected moment, the story told changes. I also expect my identity as narrator to shift in the telling, as I am framing, re-telling, highlighting, and re-producing new meaning with the anticipation that others will *hear* the words differently. In this chapter I turn my attention to the culture at ReShape and describe in detail the organisational language, behaviours and environment (Shohamy, 2006). Using vignettes (Finch, 1987), I present five perspectives of the organisation that relate to the narratives of injustice and the web of accountabilities framed in the last chapter. Together they describe a shared language, one that is divergent from those in society that reproduce ableism. In writing I offer a number of angles on a shared perspective in which reality is negotiated in the storytelling of an organisation.

The workers I talk about are composites, with their language expressing a unique web of spoken ideas that articulate culture. By culture, I mean ‘the knowledge that people have learned as members of a group, [that] cannot be observed directly’ (Spradley, 1979, p. 7). It is a culture with specific characteristics that speak about disabled people interests, in a language that responds and mediates narratives outlined in chapter four and embodies the accountability discussed in chapter five. The text of this storytelling is an ethnographic product that conveys more than words alone. The snapshots communicate attitudes and feelings; with the workers’ words the bare bones of

language, the tools, that without context and emotion lack power (Austin, 1979). It is a show, don't tell, because 'the end product of doing ethnography is a verbal description of the cultural scenes studied. Even ethnographic films do not describe without verbal statements that tell the viewer what the people filmed would see and how they would interpret the scenes presented' (Spradley, 1979, p.21). The sections end with a description of a community of practice, and the activism within a non-hierarchical structure, that facilitates a responsive decision-making within an inclusive web. Thereby articulating conversations that produce different relationships in terms of power (Helgesen, 2005).

The *poor* sentence structure in this chapter is used on purpose to reflect the immediacy of response, the staccato and punctured nature of office conversation. I hope however that the organisation's positive tone shines through, as I describe the public and the personal aspects of choice and the implication of considering disabled people's interests in a workplace. The five conversations are specifically constructed to articulate culture from the macro to micro, in line with the previous two chapters, also representing the layers of ethnographic writing identified by Spradley (1979). Together they give a representative idea of organisation's culture. Agar observed that language does not need to be tidy, that in research texts have a 'tendency is to draw a circle around language, to herd sometimes neat sentences into the corral and wrangle out the parts of speech... They are to do with wild herds of sentences, out on the open range' (1994, p 16). I am aiming here for the chaos and unpredictability of daily work, and the vignettes help draw out the tension, high expectation and fluency in conversations. These can be essentially operational, but in this text they also articulate a strategic potential. Conversations sit in context, holding positive and life-affirming ideas that stand in opposition to the more commonplace narratives that erode disabled people's sense of emancipation. Sometimes this means sitting with silence, acknowledging pain or pleasure, without threatening the fragility of the moment. What is performed through the vignettes is a 'play',

exploring how politics, community, change, choice, and individuality disrupt the orthotoxic ableist narratives found across modern day societies.

6.1.1 Vignette 1: A radical place

Monday. I approach the ReShape offices for the first time. As I park up, a voice on the radio says: “UK welfare reforms have led to grave and systematic violations of disabled people's rights according to a UN inquiry“.

The building stands in an unassuming business park on the less affluent side of ‘toon. I’m anxious, although having previously met several ReShape workers, I feel more positive about this visit than I usually might when approaching a group of strangers. I expect them to know about disability, and to have experienced the discrimination and oppression they face – if no words for it. Ordinarily, meeting workers in a workplace can be tricky. Receptionists sometimes appear shocked to see a disabled person come through their door and come out with all sorts of rubbish. Thankfully, here, things start on the right foot (joke intended).

“Hallo, can we get ya a cup ‘o tea?” [Fieldnotes]

There are smiles, then ‘hallos’. Help is on hand to sign in and drinks are kindly offered. I’m relieved: what can be the hardest moment of any initial visit slips by as a blissful non-event. No overcompensation needed, no charm offensive to calm the shocked or reassure the harried. My appearance seems largely uninteresting – what a joy! I notice a screen behind me. A newsreel is playing, the broadcasters are smiling, and their physical difference is visible. It is immensely reassuring, and has a positive powerful impact on my place in the world. I relax and breathe.

As I make my way to the kitchen, I notice the walls, white and bright, with the company logo artfully used in decoration. Primary colours and a few graphics² about the organisation's learning journey give the place a bright and vibrant appearance. As I approach the kitchen, unaware it will become my office, I am welcomed to a light, clean room kitted out for both need and comfort. People are eating, drinking and talking; they look comfortable and at ease. It really is hard to tell who is client or worker. In months to come the volume of the greeting will increase in volume, from hesitant smiles to big hugs.

From the off it is a place where I feel wanted. Clothes sometimes say lots in terms of status, but here these are all casual. I spot no suits, no designer logos or shoulder pads. I breathe again, and relax, as I'm told to make myself at home. People come, and others go. Amid the chitchat I pick up a sense of urgency and purpose.

Someone answers a ring-tone that quacks:

".... Yes, of course, you know I'm there for you, we're a team, you know that, right?" [Fieldnotes]

I want to start probing, deep, thoughtful, and insightful questions... instead I blether. The conversations are frank and honest: I hear very little pretence in people's voices. When explanations are needed, words are straightforward. Hard facts are laid bare, not sugar-coated. I cannot remember hearing an implied judgement, so often injected into exchanges elsewhere. Noticeable are the signs of respect and the boundaries preserved around those who may need them. Difficult conversations, politics or addiction, are dealt with minimum fuss and little emotion. Far from baby language, people use straightforward language stripped of irony, innuendo and the pseudo-speak so often used to fudge issues or evade hard subjects.

• ² Graphic facilitation is a tool that uses words, symbols and pictures to record and facilitate meetings. Key ideas and concepts are captured in real time on a large display that promotes "big picture thinking" and stimulates participation, creativity and focus. The pictures are drawn during the discussions for all to see, meaning that people have the opportunity to see the ideas being expressed.

It is a rare sense of belonging, being ok, safe – normal. The ease with which workers welcome new people and their ideas, a pleasant shock to have been included in a wider conversation in this our world. The language used was straightforward, simple and matter of fact.

6.1.2 Vignette 2: Beyond our walls

It's Tuesday. I arrive late and the conversation in the kitchen is in already in full flow.

A worker shouts: "if she's alone get 'er a tv!" [Fieldnotes]

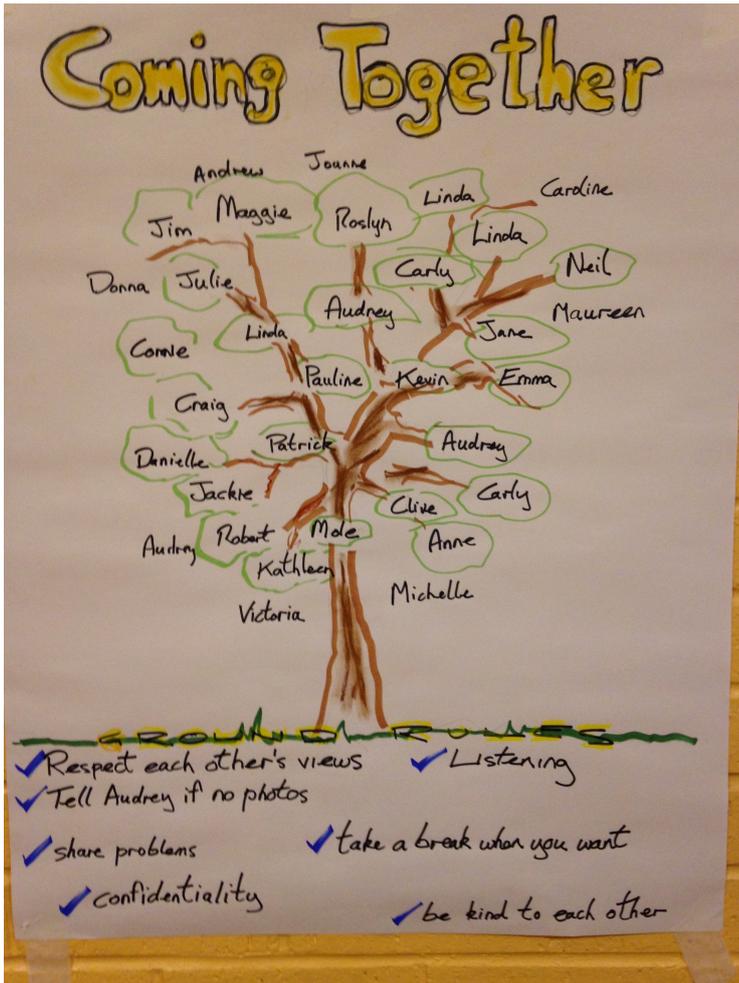
Arguing starts – there may be other things she may enjoy, activities that give opportunities to meet people and make friends. There is a quip about the need for a health and safety assessment if a person is to join in with other people's activities. This gets shouted down with laughter.

*"Do **you** need to fill in a form to go to the pub?" [Fieldnotes]*

The riposte is good-natured, but the argument is firm and the point driven home.

Later, I go to a gathering held to bring people together. Initiated by the ReShape workers and facilitated by two external graphic facilitators, the event is set up to support people meeting in a place where a community might ordinarily come together. After a great amount of community networking by ReShape workers to promote the event, the gathering takes place in a community centre. I want to meet the disabled people supported by the organisation's workers, to find out what matters to them. It begins with a group charter which includes being kind to each other, listening, sharing problems in confidence and taking breaks. Graphics matter (see fig 6.1.).

"I couldnea believe how powerful the ground rules were!" the worker tells me [Fieldnotes]



[Fig 6.1. community day]

I saw graphics used to give people time, pace and freedom: they also reassured people that they were heard and their contributions were noted. The images also served as a recap at the beginning of the next meeting. Small conversations began while the important stuff emerged during inconsequential activity, in an uncontrived manner.

Days pass... Monday once more, and I'm shadowing a couple of workers. We are meeting clients to hear about their experience of service provision. Team meetings are another example of the unusual, because they take place in people's homes, with workers sat around the client. The 'clients' are called Team Leaders, and are encouraged to say what they want, to choose their provision where they can, and to make decisions in their own lives. I see that while workers provide a 'service', they understand they are within the homes and public spaces of people's lives. Financial measures, technical aids and bureaucracy have no place in helping people out of bed, preparing lunch or meeting with friends. It is so different from other service-driven organisations where services are created before the clients even speak, and where rooms where staff do their jobs are closed to visitors. Other examples of this client-led practice include going to where the client is at

the start of a shift, paying a local cleaner to do housework (substantially lower cost than a support worker), and not ending an event early simply to suit workers' shift patterns.

As I chat to the team, they state their huge frustration at measures imposed on them from beyond the organisation. A number of workers are making plans for Christmas. They are talking about what to do to best support a client on Christmas Day. They say they will find out if another client was having a get-together, to see if they'd be happy together. When I ask if it's in their client's interests I'm given such a filthy look that I blush. It is blatantly obvious that the client's needs come first. From the support worker's perspective the question is obviously ridiculous. I feel that my questioning is at odds with our now established relationship. I notice a quality to the language, one that establishes the importance of disabled people speaking for themselves, in public debates reaching far beyond the organisation's boundaries.

'Outwith' is a Scottish word that admirably describes the 'outside'; 'beyond'; and 'outside of quality' of the culture at ReShape.

6.1.3 Vignette 3. If one thing remains constant it's change

Wednesday. I've become used to what looked chaotic a few weeks ago... The closeness of people, yet their respect for each other's space, seems to work well within the open-plan business area. Slowly, I've started to notice how easily people share their thoughts, their ideas, and their frustrations. This proximity says a lot about trust. I see that the boundaries between private and public are respected, but in addition there is a shared sense of responsibility with which work ideas are shared. It is a closeness that I have not experienced before, a fluidity of shared endeavour unlike any other workplace I have visited. In many organisations I have worked with there is a marked

difference between worker, management and leadership, but here, the distinction is hard to spot. What I initially found to be messy actually reflected an ability to think about futures, not just moving forward.

In the kitchen again, I get drawn in to a heated discussion about token economics – a coercive technique that aims to make people change their behaviour through a reward system – to *encourage* them to do what the support service workers deem more appropriate.

“outrageous practice!” a worker shouts [Fieldnotes]

I'm in the thick of it, as I discover that the incident was brought to bear on a client by a different service. I notice that the uproar has sparked a deep discussion; indeed the conversation provides a learning opportunity for anyone within a mile radius of the offices. But it only takes minutes, which is startling, because the depth of reflection is rare. The conversation is honest and frank, a shake down of both language and practice. In any another workplace I have visited, such a conversation about the abuse of workers and the misuse of language, may have been disempowering to all involved. But not here... Here the words are used to ensure client's rights remain central to the conversation.

I see how difficult it is to constantly buck the system. I appreciate how hard it is to keep up innovation. Sometimes even with the best ideas, the initial energy is hard to sustain over time, and in a crisis workers seem to need the security of decisions being made for them... if only temporarily. I watched workers negotiate with great care the things clients could take forward for themselves. At times it was the clients who needed things to be more organised, tied down and dependable. And although most often workers rejected the language of their sector, for some it was harder to keep going. Over the period of study I did witness how difficult it became for workers to think long-term as in the short-term, cuts made practice difficult. Yet, overall I had the feeling that

the workers followed the wishes of those they support. I heard workers organise working hours around activity:

“Because I know you like walking, could you meet them in town and spend a few hours in the centre, please?” [Fieldnotes]

I listened to the kindness in the use of language, the informality that was respectful and thoughtful. Over many months I was exposed to a very alternative culture, circumstances in which it felt normal to be disabled. It was a refreshing and life-affirming challenge to my own norm, finding myself slap bang in the middle of a conversations about rights, when elsewhere they are so often about cementing things through worker convenience and service-driven targets.

6.1.4 Vignette 4. People count!

It is Thursday morning! I can't help noticing the smile on my face and the bounce in my step. A ReShape day is always a happy day! I'm heading into the Finance Office. The filing cabinets along a partition carry 90+ cardboard files and on each, there is a photo of a client. The preferred term is 'person-we-work-for' I'm told. Not only are faces recognised, but also most of the finance team are able to tell me about habits, preferences, and interests.

The amount of detail is staggering, but means dealing with hundreds of small amounts every day, such as taxi fares or train journeys and so forth. Every client is in control of their own finances, an Independent Living Fund is the term used for their 'pot' of money within the organisation's flow. I am told that one person was overpaid on one occasion, but the client flagged up immediately they were up £20: "It's no' mine!" The 'pot' allows for fluctuations: if there is a little left after a hospital stay for example, this goes towards extra help a few weeks later. Not only does uphold a right to

own one's own purse, but the pot system allows for the messiness of life... broken taps and birthday treats. The changes in cost patterns associated with new interests, education achievement and cycles of relationships are part and parcel of supporting lives lived to the fullest.

I've a meeting with the business manager but I end up explaining my research to the whole finance team. It is a tiny office. I am glad to be able to fumble my way through it, and enjoy the first opportunity to let others speak: I am keen to find out what they care about. My first question concerns people's freedom, choice and happiness... As I watch the blank faces, we all take a step back. I ask them: "What's good about the job?"

"It's about human rights, feeling and people. What we do really matters. We're guardians of people's purses!", says a finance worker. [Fieldnotes]

Very quickly I am told it is all about human rights, it's about the people the organisation works for. Every amount matters, I am told, because it really is all about people having choices. I have rarely come across workers more eager to make sure people can get every penny possible. Usually it is the other way around. I am told £5 can make a difference: people have so little that there's merely a breath's space between getting by and going under. What emerges is how important the finance team view their role as stewards of other people's money. I am told they act as custodians:

'We keep an eye across the office on how time is spent!' I imagine fairy wings, a tear threatens... thankfully there is laughter. [Fieldnotes]

They tell me the word 'hour' is a zone of tension. Hours, workers feel, is a word they use only with funders, but is a waste of time within the organisation because providing a detailed analysis of hours worked neither helped or supported clients.

"I can't believe it... I know my clients' needs are the most important part of the job but I've spent all week chasing hours [work-sheets]" [Fieldnotes]

Many workers say they had spent so much time chasing admin they have little left to really explore they clients wishes much further. I get a feeling that despite strong internal values, outside imperatives put additional pressure on workers. The irony: this is at the clients' expense. Sometimes workers need to do things that in no way articulate the accountability they wish to support that is achieving more personal freedom for clients. As a worker makes clear:

“Activities should be dictated by individual choice and preference, each in relation to what matters most or least to each individual”. [Fieldnotes]

Presumably they mean that this is not achieved by the number of hours spent ticking generic tasks on a timetabled list. Workers tell me that they know their time is a precious commodity. They tell me that while in the name of accountability they are repeatedly asked for the number of hours they work, no-one ever asks them whether it was time is well spent – legitimate. Producing lists of numbers, they say, does not prove whether needs are met, new possibilities considered or holidays booked. They go on to say that it is measured incessantly by others, workers who do not understand the jobs they do.

“It is perverse” they cry “measuring hours worked actually costs us time.” The irony! [Fieldnotes]

They want me to know that notions of accountability put in place by funders takes money away from the very people who need it most. They view money only as a route to greater wellbeing for clients. Money is not a measure in its own right. It is how it is spent that matters here; it is knowing what people care about that *really* matters. Their voices rise as they explain this to me. *They* know whether or not hours are spent on clients' needs. As ever it's not the size but what you do with it that matters! Counting hours weighs the pig, but does nothing to feed it. Indignation is palpable, and it is apparent that negotiating this tension is a daily chore; the team sits between two worlds and two languages.

They explain to me that the organisation holds no common bucket. They tell me that a ‘pot structure’ individual control would be lost and decisions could be made that would harm clients. They speak with passion about the scale of impact, and how small differences or lack of flexibility could quite easily rob people of some very basic life choices. At one point we all had tears in our eyes as one of the team told the story about one of the clients bringing in a bunch of flowers to thank them for the money they’d received.

“You don't get flowers when dealing with ball bearings!” [Fieldnotes]

They tell me that having no reserves robs people of what they need in times of unplanned expense – such as an outing or birthday celebration, costs that so many can take for granted. They speak with animation and empathy about their interactions with clients. They are proud of the importance of their work, the trust they hold in the amounts of the money they handle.

They may need help to do this, but ultimately the choice is theirs, they have control: “I want a worker to go bowling on with me on Thursday, but no one around me on Friday - I don't like people around when I want to rest”. I watch as the client make their wishes very clear. [Fieldnotes]

I observe the emotion in their faces: this is finance, but it is obvious the team know it is the clients who lead the organisation.

6.1.5 Vignette 5. Hope and vision

It's Friday... party time! Celebrations are a regular part of ReShape life. There is something uplifting, hopeful and positive about clients and workers coming together to celebrate the organisation's milestones. These gatherings give people an opportunity for storytelling, to celebrate each other's stories, achievements and successes and the positive progress in their lives. Within every articulation of ReShape life there's a good feeling of anticipation, one that appears to enable each individual to make and maintain choices in their lives.

“We all need somewhere we are safe to be who we are - loved”. [Fieldnotes]

As I watch, people meet and greet each other with warmth. A louder ‘roar’ ripples through the crowd as a bubbly gentleman arrives and goes around saying ‘hello’ to everyone present. Enthusiasm about each other's news is obvious, with hugs, smiles and exclamations at every word shared. I hear conversations that talk about being no longer needed, when being replaced by friends and neighbours.

One of the organisation's creators states: “Organisational practice is not most important... we are 'citizen enablers' ... Bigger than sum of our parts... By your side/sits beside/side by side ...” [Fieldnotes]

Faces are known, names recognised, no one is left out or ignored. The sense of belonging is tangible. The subtlety of some support workers is truly artful, moving in to help and stepping back with equal ease. I am aware that what could pass as easy work, requires tact, empathy and understanding. But my surprise is always at the joy it brings to workers who talk of the happiness their work brings them. I see ease and fluidity there is in every situation. I can hear it, feel it and touch it... hope? It's there, like nowhere else, in the mundane, in every word that speaks of what is possible.

Part of the event today is listening to people who were institutionalised before they came to ReShape. It is a harrowing to hear. They speak of having no keys, no first name, no choice, and no friends. The point is that however cosy, an institution is an institution, not a home. At home I have a name, a key, I can come and go – or not. I can decide when I wake, eat, wash, shop, and most crucially, *with whom*. A colleague reminds me of my freedom in the cost of institutionalisation:

“I never forget meeting a young man with Down's Syndrome asking me how I'd feel if my home was sold with me in it.” [Fieldnotes]

I am deeply aware of my privilege, luck in a community where an accident of birth gave me freedom and opportunity. As I listen to those deprived of community connection, put in enforced

segregation and humiliated while robbed of their human rights. A blatant disregard for the human need for respect, dignity and hope for one's private and family life, home and relationships.

ReShape clients are liberated by workers intentionally making decisions at their side. But they still have to deal with the fear and anger caused by years of harm. I see that the closer the decision is to the receiver, the less likely it is that workers will forget the power they have in the lives of others.

6.2 Stepping forward

The story told in this chapter makes real the language that speaks with legitimacy to the narratives of injustice faced by disabled people. Through the telling of events in this chapter, I have described how life at ReShape is grounded in a deep understanding of human rights and personal choice to enable very different outcomes for disabled people. Legitimacy here is not the search for approval or avoidance from disabled people as a group in society, as proposed by Kaplan and Ruland (1991). It is a voice found in the mouths of workers when they are speaking to their clients' power – a voice that alternates between welcoming the personal, looking beyond the organisational, mediating the present, counting the priceless and happiness in the future. I have written about the acceptance, closeness, and kindness of teams. I have highlighted peculiarities which I have rarely encountered elsewhere. I have conveyed conversations, and their fluidity, their intentional and strategic intent in the practice of storytelling - particularly critical for individuals for whom a future has been drearily prescribed or extinguished through physical restraint or chemical cosh. Finally, I summarise these perspectives by relating the text back to the web of accountabilities that support the interests of disabled people. The vignette perspectives offer a rich description of the working activity that is so characteristic of the ReShape culture, a way of working that is divergent in that it sits at odds with more usual conversations about support in other similar organisations. The storytelling offers us a glimpse of what is possible in achieving both entitlement and realities in terms of human rights.

Interlude

Thankfully, as the snapshots above describe, wellbeing is a reality people like Jean in places where their story matters. When, despite repeated cuts in funding, her words remain key to the decisions in her life. Workers around her use words, and act in ways, that shield her from the toxicity in the landscape. They talk often of her needs, wants and wishes, and whenever possible they help her to go beyond the limit of what she knows. In the story above the writer presents a sensitive telling of a world without toxicity that in its wording protects Jean from harm made a reality elsewhere.

The field is where culture happens, the words in the landscape influence the conversations that control Jean's life. I went looking for people who know Jean, who unencumbered by the prejudice, know her a storyteller. Because its a familiarity with her experience, that prevents the toxic myth, a distortion that spins a prejudiced view of her life. Therefore, they were likely to tell stories that reflected the truths about her, not some made up nonsense based on hearsay. I observed their working lives, listened to their conversations and got to meet the people they met. I asked questions about their work, the barriers they faced, the help they received and the ideas they used to make sense of their working lives. I watched, I listened and became familiar with their storytelling. I then compared their stories to others, stories in different organisations, tellers at conferences, accounts on the net and in print. I wrote about their ideas, and looked for other storytellers telling similar or alternative stories.

*Successful communications combine a sense of urgency with a sense of possibility and understand that the way an issue is framed is at least, if not more important than facts and evidence... in putting disability at the heart of the debates and shaping our collective future.
(Crowther, 2018)*

Chapter Seven

In the chair

7.1 People matter!

This chapter begins a reflection on the articulation of language and culture re-presented by the vignettes in the last. Back in my office, sat in the chair, it was time to make sense of the story of the visit, informed by the words and action in the field. In answering the question: ‘What struck me?’ a text soon emerged, telling of the organisation’s culture by describing its atypical, often divergent, characteristics. As a reflexive exercise, I have arranged my reflections on the visits – the storytelling in the ethnographic text – under headings that follow the numbered sections in chapters four, five and six. That way, the sections answer the call to acknowledge injustice outlined in chapter four, through the frame of dialogic action in the web of accountabilities put forward in chapter five. Thus, ‘global inequality’ links to ‘political dialogue’, observed on site in ‘a radical place’, leading to sections in the following two chapters about ‘radical hospitality’ and ‘investment in possibility’. This pathway enables an exploration of language and culture that responds to the interests of the disabled population by speaking against ableism with legitimacy.

In the story told, the previous chapter created a reality that stands in opposition to the narratives of injustice disabled people face. The web motif is apt again, as threads of conversation are tied together to illustrate different shapes of organisational chatter. It is a conversation with no beginning and no end – except in text. However, its weave creates new ideas – certainly in my own mind. I am aware that the writing may spell out alternative futures - our stories. For I now think that it is within the threads of conversation that people connect, and it is within relationships that the meaning of humanity is told. As this report from Centre for Trust, Peace and Social Relations states in relation to indiscernible quality and emotional value of help within communities:

Everyday help and support is a spider’s web. It is a structure composed of individual but linked threads, combining fragility with considerable flexibility and strength. Equally, importantly, it is often almost invisible to the naked eye, until revealed by the angle of the sun, a sharp frost or droplets of mist’ (Anderson et al, 2015, p.9)

The ‘sharp frost or droplets of mist’ are created by the ethnographic text that draws attention to words and action that may otherwise seem mundane. Reflecting on this fragility, my writing at this point becomes more cautious, indicating an exploratory tone. The use of the first person here conveys hesitation. I sought to avoid the jargon that ‘covers up, and otherwise hides from view matters that might well be ambiguous, poorly understood, or contestable’ (van Maanen, 1998, p.28). Equally, I sought to strike a balance between the experience and the academic; ‘Too little or too much of either is presumably deadly’ (van Maanen, 1998, p.29). The reflexive process was used to challenge my own assumptions, as far as possible, and to help deliver a trustworthy narrative that demonstrated respect the organisation’s storytellers (Isaeva, Bachmann, Bristow, & Saunders, 2015; Gibbon, 2012). The overarching aim of these sections is to make the implicit explicit by showing ReShape’s cultural norms (Lave & Wenger, 1991). In the spirit of Freire’s (1970) articulation of consciousness ‘talking up’ challenges a wider culture of silencing. Identified in Chapter Two, talking up acts as a response to the void, voicing what can be invisible to many. The text can be equated to a demonstration of activism (Whitburn & Goodley, 2019).

7.2 Talking up radical hospitality

In its radical nature, ReShape’s culture of hospitality struck me as an active embodiment of the accountability described above by political dialogue. This is particularly so because a desire to accommodate difference continues beyond ‘a welcome’ in a hospitality that aids the belonging of those marginalised by society’s ableism. “You are wanted!” is not a phrase disabled people hear often – trust me! At ReShape I experienced hospitality as a repeated invitation to participate, or not! It was not a welcome with a request to fit in, but an on going affirmation of wanted contribution. Conversations with workers proved its radical intent, as many recognised that disabled individuals faced a widespread inequality. When asked, they were also quick to recognise that feminism, black power, and gay pride were tangibly more recognisable than any disability equivalent.

I was struck by the depth of reflection in many of the daily exchanges, as workers often described the injustice disabled people face and spoke against it. In less specialised settings, workers can be anxious about meeting disabled people for the first time. This initial fear is understandable, because whole populations are steeped in an orthotoxic soup. However, this fear means that workers can unwittingly speak in discriminatory, oppressive or abusive ways. Acting on the belief that disabled people are inferior (Barnes, 1991; Deal, 2007), workers often rely on society's narratives and their own assumptions based largely on negative stereotypes (Gladwell, 2008). It struck me that at ReShape, workers seemed to have identified these stereotypes, recognised that they fed myths and artfully directed their criticism of common misconceptions towards the prejudice and wrong assumptions with both strength and humour. This helped diffuse embarrassment for those who did not share such understanding. It is rare to witness such incisive critical thinking in an organisational setting: hidden behind what appears quite a harmless banter, was a talk that could be qualified as a unique type of rebellion.

It was a relief not to have to give an explanation for my impairments. It struck me that elsewhere the private/public divide is often abused in the name of monitoring or adjustment. I did not need to request help or adjustment, or fill in a questionnaire on a personal matter to get help. It seemed that at ReShape impairments were understood as common in occurrence, and therefore respected as part of human diversity. Requests for help were expected – from everybody - the alternative anticipated, and the quirky celebrated. It struck me that workers did a lot to ensure that people generally felt wanted and valued. It was unusual to witness just how much workers were comfortable with interdependence. As a group they formed a relational structure, a social weave reminiscent of a cloth or fabric that tied together individuals and their individuality. In their work with disabled people, workers were enthusiastic, generous and upbeat. Thus hospitality was expressed in tangible

action and deliberate language. Workers told me they found the attitudes of their ReShape colleagues very different from those of colleagues elsewhere. It was the shared values, they said, that they loved most. Even when removed from direct contact, I was aware that workers knew the recipients of their work by name and clients had photos identifying individuals by their first names. It was apparent that workers were keenly aware of the cost of wider social care cutbacks on people's lives, and that these were driven by a political narrative of austerity spoken about beyond the organisation.

At other times in our conversations I was struck by workers' ability to put aside their own power, allowing different questions to be asked - ones that encouraged clients to say what they wanted. Encouraging participation is often put on hold for people with complex requirements. Self-direction is so often lost in institutional rules, societal assumptions and people's need to act for them. While holding the space, strong operational values seemed to allow fluidity without compromising on the principles and values. It struck me that as a community of practice, the whole worker group acts as a buffer, helping to slow down the seemingly relentless pull towards a singularly financial accountability.

Organisational practice is not most important... we are 'Citizen enablers' ... Bigger than sum of our parts... By your side / sits beside / side by side ... [Fieldnotes]

At ReShape, radical practice has generated hugely successful outcomes for disabled people, and compares impressively with traditional services. Globally, ReShape's ways of working with people with complex requirements are recognised as pioneering, with interest in ReShape extending as far as Australia. While holding the space, strong operational values seemed to allow fluidity without compromising on principles. It struck me that as a community of practice, the whole worker group

acts as a buffer, helping to slow down the seemingly relentless pull towards a pared-down notion of financial accountability.

7.3 Talking up citizenship

In contrast to national debates that frame disabled people as a cost to society, I was heartened at ReShape to hear most clients described as community members. This articulation stood, I felt, as a divergence from the consumer role – worse being a client - within a story with a market storytelling. Speaking of people as citizens restores a fuller sense of accountability within a wider public-facing dialogue with society. Also, the way workers positioned their clients within local relationships spoke of their unconditional right to a community life. However, it is essential that workers have good local knowledge. It struck me that as a public articulation of accountability, securing interdependence – not independence or dependence – means securing the typical web of relationships many can trust: family, friends, associates and neighbours.

It struck me that ReShape workers were able to identify the private and public boundaries many know so well, in order to work across them and break down barriers to more ordinary relationships. Typically obscured by an internal organisational focus, the public dialogue involved speaks to what matters for communities, but it is often forgotten in business conversation. That is, customers are often asked to comply with business habits, rather than workers adapting to the personal language of the public they serve. ReShape has begun working from smaller hubs based at a local level, and I felt the creation of these local teams has fostered a more nuanced way of talking about the lives of disabled customers as citizens – not recipients of service. In turn, I feel this change in conversation has led to more interest and activity in the lives of recipients of services as community member. I was struck by a strong emphasis on ordinary language, often used against a wider sector narrative that is laden with working terminology and business acronyms.

Disabled people are not necessarily community members: like other they need to share an interest and its language to share in a network. As Kozinets (2015) describes, communities are ‘worlds of meaning’ that exist purely because of their continued adoption and use in the minds of their members. It is a view that brings together the shared direction of the public being and the distinctive multiplicity, heterogeneity and unpredictability of their personal selves. In navigating these adjacent worlds, I watched workers articulate both the personal and the private, within the more public spaces of local networks. For example, language used was more explicit in describing the fullness of clients’ ‘community’ lives, than the single dimension that workers often refer to as ‘leisure’ time in a business narrative. It is not the words, but the breadth of human rights behind the language that spells the difference in meaning: expressing the difference between the joy of swimming with friends, and attending a length-swim session at the pool. By avoiding the terminology of business, and by tuning in to their clients’ own words, workers appeared to mediate the dehumanising impact on their clients of business narratives – especially outside the jurisdiction of conversations in a market space. It struck me that there was also a need for workers to understand the characteristics of business and community narratives in order to separate the later from the former: any lack of awareness of the impact of ideas implicit within national debates could have consequences for the empowerment of the people they are paid to support.

I was struck by workers’ strong awareness that they were stepping into community spaces in which their language had to adopt a character more suited to shared interest in order to avoid imposing oppressive vocabularies found elsewhere. The skill with which workers moved from a work conversation to a public one demands clarity, because the later is more oppressive, giving workers power, should they wish to take it – or worse, ignore it. It struck me that by using language to respect private boundaries, workers could also mediate public narratives, giving clients more power

than they were used to having. I am more familiar with organisations that employ a business narrative even in clients' homes, and have no words for a more public conversation about citizenship or community. The ability to change the meaning within a conversation seemed important in supporting clients' empowerment, their choices, their aspirations and their relationships with others.

Skill was apparent in the fluency with which some workers pointed out business narratives, and at other times how market ideology crept into their conversations when they failed to concentrate. They told me how hard they found it to maintain divergent conversations:

'It's like travelling up a downward escalator,' she said. 'One moment of inattention and you are back on your bum!' [Fieldnotes]

Confidence was key. It struck me that workers also benefitted from reassurance about their meaning of community, and felt their own words clashed with what was more widely said about disabled people in national debates.

The word 'hour' is an example of the way one word can carry different meaning, leading to conversations where languages collide. 'Hour' is often employed as shorthand for the price of a worker's time. In a market narrative, therefore it represents a unit of work. As such, it is devoid of any characteristics that would qualify the worker as accountable, or the work as legitimately aiding empowerment. ReShape workers were clear that despite its national currency, in the organisational narratives the 'hour' held little meaning in terms of care. This struck me as significant, because while pounds and pence symbolise efficiency in many debates about disabled people's lives (costs in grants and funding), the power given has little meaning in articulations of human rights, freedom from harm or justice. It is not easy to hold contrasting conversations in the face of a daily barrage, and the seductive draw of a market narrative to validate the legitimacy of funding is overwhelming.

Speaking about what matters to people – that which contributes to wellbeing – involves unlearning business speak and standing in opposition to it. It means letting go of ideas about growth, productivity and sales and trusting exchanges to take place within networks of relationships that are priceless in spaces where people flourish.

It was always ReShape’s goal to give institutional survivors the fullest possible community life. However, within an era characterised by austerity measures often aimed directly at ‘benefit claimants’ (Wiggan, 2012), this initial aim has sharpened lately to a wider stand against institutionalisation. This form of activism is effectively providing an argument for a better hour grounded in human rights *for less*. ReShape, as a voice of a working community in national debates, speaks against the way that the business narratives of services dehumanise disabled people to the point of violence. By being labelled as a recipient, user or consumer, disabled people lose their voice in public debate. In some circumstances, some are locked away, with little chance of freedom from enforced shared housing and assessment and treatment units (ATUs).

7.4 Talking up choice – pot structure

The story told in Vignette 4 is an account of an innovative dialogue that mediates for the more widespread ableist narratives led by working mindsets and their institutional arrangements. An innovative dialogue seems to lessen the toxic impact of an orthotoxic culture. But while it is easier to start than to maintain, even in an organisation set up to fight institutionalisation, it is difficult to keep telling a story that diverges rather than opposes dominant storytelling. As Caroline Criado Perez explains, in policy making circles where decision-making is made by ‘white able-bodied men’, the unintended ableist-bias is what ‘de Beauvoir meant when she said men confuse their own point of view with the absolute truth’ (Criado Perez, 2019, loc 439). Also, because so many businesses depend on government funding to survive, they become unresponsive to the networks of

relationships – the marginalised groups – which they are paid at a huge cost to society to serve. Thus the ‘multi-agency structures that have emerged to address the social problems created by industrial decline have become a problematic industry in themselves’ (McGarvey, 2017, loc 276). Challenging behaviour was thus seen as ‘feedback’, and interpreted as an act of freedom against the oppressive world of institutionalisation.

At ReShape, the divergent is embedded within the innovative structure that holds the culture in place. As Helgesen (1991) suggests, direction and distance in lines of communication create shapes: these are important to culture because of their impact on all aspects of an organisation’s language. At ReShape the lines of communication are upside-down, as they run from client to workers. Similarly, the financial flow is an example of power-reversal, as each client has an Individual Service Fund or individual purse, a ‘small pot’ of money that is uniquely theirs [restricted costs fig 7.2]. From their ‘pots’, clients known as team leaders, pay into the organisation [capped costs - see fig 7.2], however, *their* Individual Service Fund is not viewed as a part of organisational account to be divided. This means that money is owned equitably, the sum based on each clients needs, and viewed as the individual’s rather than a same-size share of the organisation’s bucket (see fig 7.1 below). It struck me the nuance of a bottom-up structure was barely perceptible when first encountered, but on reflection, its impact was critical for wellbeing, as it also led to the considerations for privilege discussed next in terms of financial dialogue.

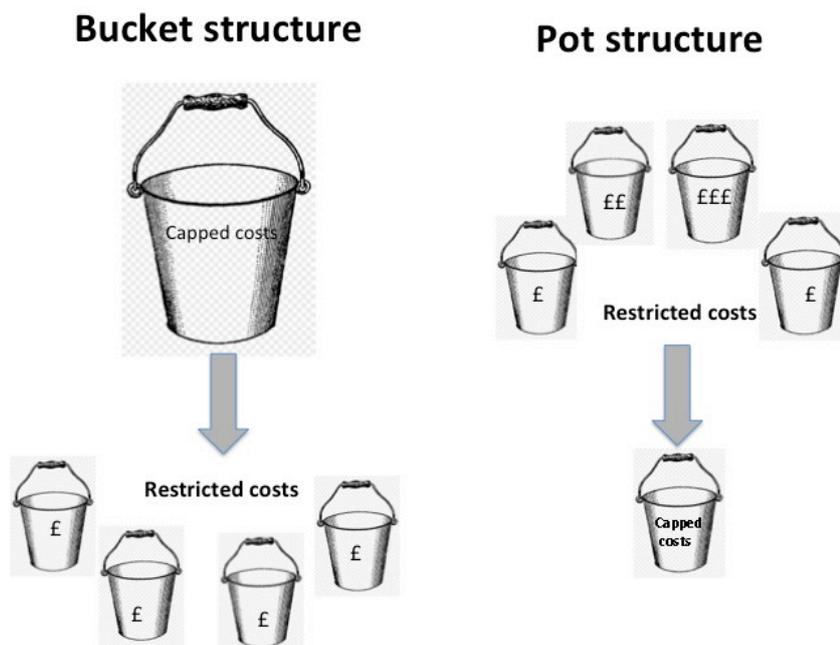


Figure 7.1 Bucket and Pots

The funding structure encourages a human rights imperative, not same-size portions, but a respect of individual need. This makes a great deal of personal choice possible by allowing options for preference in spending. The culture within the structure opens a space for dialogue that speaks to wellbeing: it frames its divergent nature in terms of alternative and emergent narratives – not focused solely on improvement, but extending accountability to a marginalised group. A innovative dialogue demands insight into the varying amounts of support required, revealing the requirement for support as the *right* and different amounts the *entitlement*, through which clients are treated *equitably* – not *the same*.

We talked about equity vs equal share; she agreed the two are not the same! [Fieldnotes]

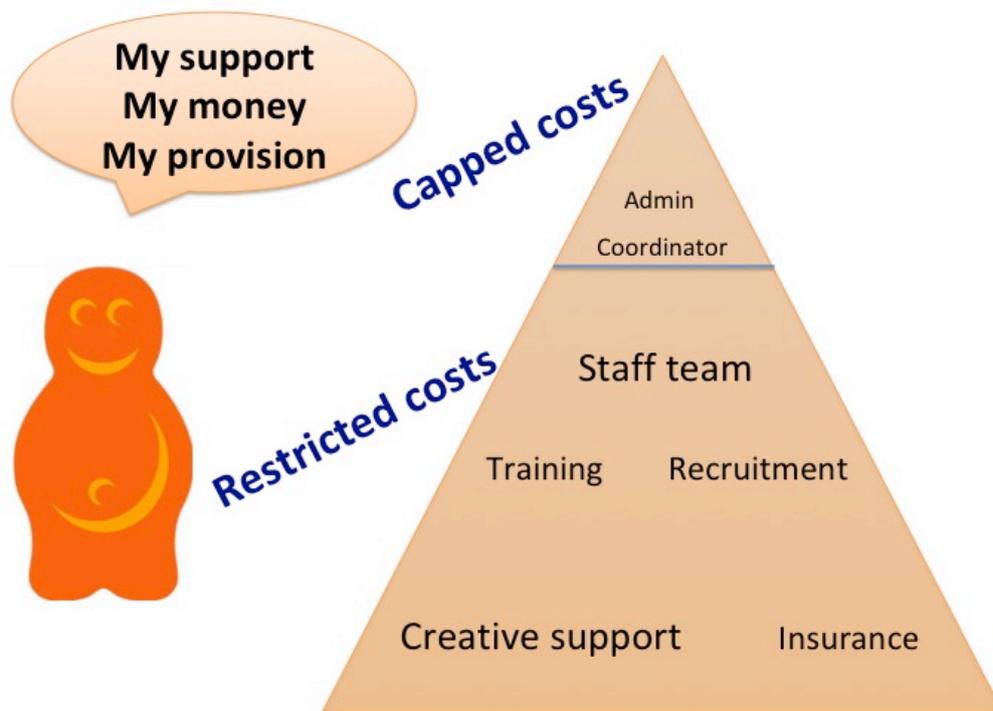


Figure 7.2 restricted and capped cost in Individual Service Fund

It struck me that the bucket/pot distinction has a fundamental impact on the direct control money can leverage. With all calculations beginning with the pots, clients leading the teams that support them, had the choice and flexibility so often erased by a narrow focus on ‘need’, removing the wellbeing imperatives of ‘wants’ and ‘wishes’ underpinning resilience and health (Wilkinson, 2005). When enabled by the pot structure, workers could demonstrate their accountability: unlike a bucket system in which choice can be denied, they focused on the small details that are important to people’s happiness. It is the detail that pennies deliver that can be life-changing. As a manager explained, £5 either way and someone’s weekly shop will disappear:

... they stated emphatically that “the devil’s in the detail”. It wasn’t like counting pencils: small amounts really had huge impact on people’s lives [Fieldnotes]

By placing money in the hands of clients, the Individual Service Funds support equivalent but unique outcomes in terms of importance, enabling choice, dignity and self-respect. Starting with personal choice, each support package is as unique as the individual it serves.

...She smiled and nodded with enthusiasm, saying that effectiveness is only possible with a flat and bottom-up structure... It requires few layers of management but lots of accountability by every worker in terms of ethical judgment [Fieldnotes]

What struck me was the intentionality of speaking to disabled people's rights, implying a social contract existing between ReShape and people marginalised by ableism in society and answering to a lack of privilege. I noted this was driven by a surprising understanding of their own experience in a hostile world in which they strived to make space safer in both the organisation and in homes. Innovative dialogue flourished, with reference to Helgesen (1991), in the short distances between people. This proximity, in turn, led to a closeness within their relationships that helped empathy (de Waal, 2009). Workers acted as mediators, particularly for those who have been maltreated and abused in the past, restoring option and creating space for choice.

7.5 Talking up control and wellbeing

A financial dialogue needs to deliver on a complex articulation of individuality, not the individualism linked to consumerism, but activity grounded in human rights. Therefore, scarcity should not be justified by financial constraints imposed by the narratives of policy (Wiggan, 2012). Money and power are linked, with the former allowing activity to express the later, and where cost is higher for those facing systemic discrimination to scale society's barriers. It is control that delivers on wellbeing, through the options it offers by way of financial stability (Marmot, 1993; Layard, 2005; Diener, 2008). Furthermore, while money serves to increase happiness to the level at which needs are met, beyond that the impact of money diminishes and eventually levels out (Layard, 2005; Fredrickson & Cline, 2009; Marmott, 2015). If we work backwards with this logic, this means that without needs being met in the short term, anxiety and lack of control can lead to harm in the long-term which may negatively impact resilience and health (Marmott, 2015). Whether choice can prevent illness is yet to be evidenced: however, so far, wellbeing does seem to be a pretty good indicator of long-term health (Seligman, 2011). The framing of financial dialogue refers back to the distortion situated at an individual level, the miss-authoring of disabled people's stories that robs individuals of the right to tell of their own experience in the face of hardship. The legitimacy of such conversations requires more than acceptance of the *status quo*: the aim of exchange needs to be anti-ableist in its intent, in order to raise elements of hardship typically suppressed by the misrepresentation of disabled people.

While ReShape is a business (making conversations about money rightly critical to its continuing sustainability) its conversations focused on rights. Enabling people to flourish was an imperative, not the chore often associated with social care as a cost. Again, a misrepresentation omnipresent across society's narratives, that adds to the toxicity heaped on the disabled population. It struck me,

that the way money is spoken about at ReShape was different from other organisations, including those dealing with the disabled population in their purpose.

... the external auditor described the financial accounts as 'permanently exceptional', saying that the rest of world catching up with the way things are done within the organisation. [Fieldnotes]

Financial dialogue was used to help clients make choices about their lives and not to limit their choices or impose restrictions. The freedom to manage their own pots meant not only that clients could make decisions on how to meet their needs, but could also look beyond them to seek enjoyment and find pleasure in achievement (Seligman, 2011). I observed that space for reflection was important, giving workers time to think about alternative options for their clients in order to facilitate an offer of information to aid opportunity and choice.

Workers spoke of the need to rewrite rulebooks in order to articulate more ways of enabling disabled people to have control of their own money. This meant the culture was accepting of chaos (or movement, at least) as flow, however tumultuous, is critical in change. This jars against the typical conservative nature of goodwill that characterises the many disability organisations. ReShape's culture seemed to hold change at its heart, and this helped workers' practice to be divergent from the norm. For example, speaking to clients first:

... the funders asked for details of a care package... "I said this was impossible before a conversation with the client that would identify what help she wanted in her life." [Fieldnotes]

In times of upheaval, however, reaction replaces reflection and takes away the depth of insight needed to remain divergent (Kahneman, Thinking, Fast and Slow, 2011). Fighting external pressures, workers admitted a monetary focus where it could hinder an otherwise human rights intent: it is easier to count units, hours or euros, than to measure impact in terms of ethical considerations, participation and respect of all individuals equally.

Workers referred to the ‘money talk’, a narrow understanding of financial dialogue that overshadowed the conversations about their clients’ needs. They spoke of stories where financial constraints gave workers power over the disabled people they worked for, such as missing a birthday or leaving a restaurant early, because worker-hours could not allow for a shopping trip or a later ride home. Workers told me that paid relationships tend to give power to the person with a job title over the client without one. I was struck by their fluency in a financial dialogue which had a depth and nuance rarely heard elsewhere.

Human rights were important and at the core of organisation purpose. Workers were stumped when I asked about monetised amounts possibly eroding this notion in practice. [Fieldnotes]

For those outside ReShape, working with budgets made only of numbers, it can be easy to ignore that a worker in someone’s home does not make that home their office. Yet many services impose language, procedures, rules and technicalities that can institutionalise people with their own home. It struck me that self-directed support is only possible when structures, such as ‘pots’, enable clients’ decision-making. An organisational ‘bucket’ approach, where money is perceived as owned by the organisation, and divided into equal shares for each client, is inequitable.

I noticed how financial dialogue extended beyond the numeric, as workers took time to explain their responsibility and told of deep frustration at the impact of an external monitoring, viewed as technical accountability, which placed demands on their time.

...it's like flying an aircraft: we can't find time to land in order to decide on a new route, with outside demands linked to efficiency measures, we lose time – time lost for the people we serve. [Fieldnotes]

As the metaphor illustrates, workers often struggled to find time to step away from operational tasks, in order to have the fuller financial dialogue that helps define strategic direction.

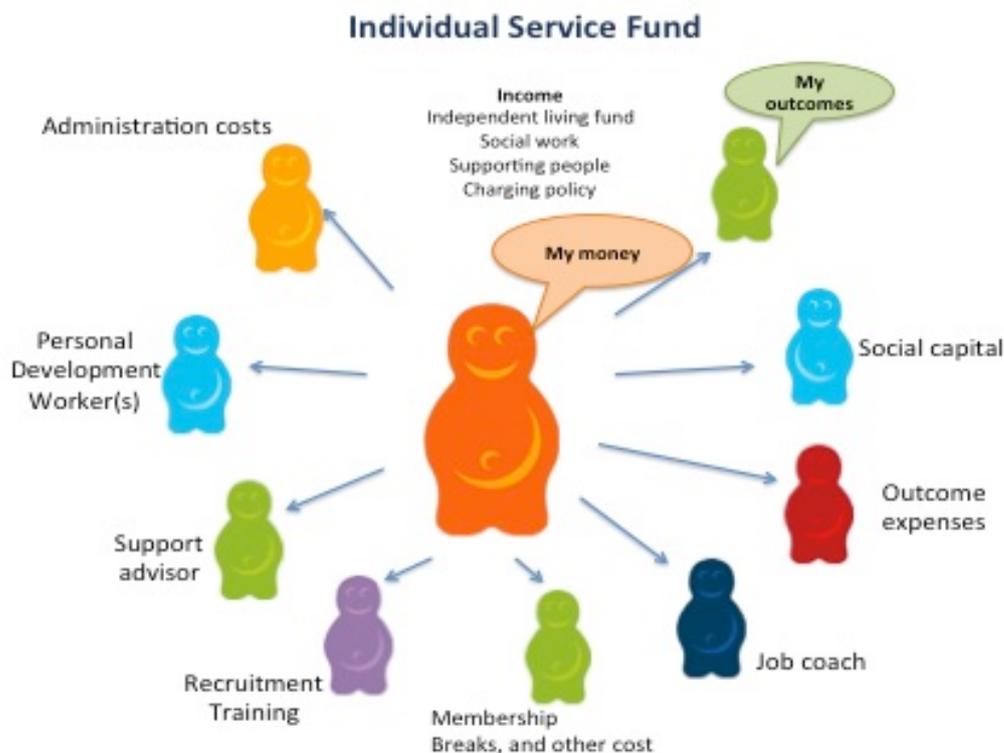


Figure 7.3 Individual Service Fund

The broader dimensions of financial dialogue were revealed when I shared a thinking session with a team leader and a facilitator who has deep knowledge of Person Centred Planning. What really stuck me was that on the surface, service-led and person-led practice *can* look similar. For example, two people moving in together can seem like a typical flat-share. However if they are actually being pushed into it, it is far more likely to be a ‘group home’. By not *choosing* to live together, a house share is not freedom of choice but an underlying misuse of institutional power that denies a human rights imperative discussed above. I was struck by how much number-crunching was named as ‘accountability’ by institutions funding clients, but how the procedures involved took up time (and money) away from the jobs that could help the service be more accountable. Furthermore, with accounting software available only to funders and not the organisation, the finance team bore the burden of having to provide an analysis of hours worked. I heard this

observation expressed often. For example, when a manager said they had spent much time ‘chasing hours’ that they had not thought about a client’s actual wishes. It struck me that a business narrative that failed to qualify wellbeing, or articulate discrimination outside the organisation, placed huge expense on workers by pushing them into conversations about money that fell short of a financial dialogue within the web of accountabilities frame.

7.6 Talking up anticipation

It struck me that accountability – defined as a conversation stretching further to articulate people’s future as citizens – goes beyond viewing them as clients. A civic dialogue, therefore, is a difficult one to expand on where more widely society understands accountability as little more than cost efficiency. Yet civic dialogue helps articulate an understanding of disabled people as community members and as storytellers.

Anticipation is not just betting on the future; it is a moral economy in which the future sets the conditions of possibility for action in the present, in which the future is inhabited in the present. Through anticipation, the future arrives as already formed in the present, as if the emergency has already happened. (Adams & Clarke, 2009, p. 249)

It may be the language which frames disabled people as entitled to a community life enabled an accountability based on a fuller voicing of their wishes. As Adams & Clarke suggest ‘anticipation has long been a component of political practice: decolonization, Marxism and feminism all rely on conjuring the possibility of new futures’ (2009, p. 248). This suggests that anticipation is key to innovation, because creating something new is different from fixing something broken: in strategic terms, ‘find and fix’ falls short of predict and prevent. Working on the positive supplies its own energy, as the wellbeing literature suggests: positive emotion in the short term is key to securing change in the long term (Huppert, Baylis, & Kevene, 2005). Understood as happiness, subjective wellbeing in the long term ensures health. However, its determinants are wide and varied and few require the involvement of health workers (Marmot & Bell, 2012). Although to avoid illness,

happiness cannot be stored or deferred, positive attitudes can lead to resilience in new circumstances, as wellbeing stems from every present moment (Gilbert, 2006; Layard, 2005; Marmott, 2015).

At ReShape I was struck by the overwhelming positivity in conversations about the future. *Wishes*, not just current *needs*, were included in the cost of a person's Individual Service Fund. This added purpose to preferences, supporting a long view of a future to which they might aspire. In wellbeing terms, this intent chimes with a requirement for daily happiness to ensure future health: more than pleasure, it also includes positive emotion, engagement and meaning, as suggested by positive psychologist, Martin Seligman (2002). While he has now added to this list to define flourishing, it struck me that hope, trust and knowledge are good as primers on civic dialogue, as they extend conversations to secure the anticipation, participation and shared understanding that speaks against a individualist narrative. I noted that an articulation of anticipation in conversations about long-term planning is unusual in organisations with disabled people as clients. The immediate need is often the focus, calling for clients to justify what they cannot do in order to get any support. Furthermore, talk of change, for better or worse, is typically absent in organisations where disabled people are viewed solely as clients – needy and deficient (McKnight & Block, 2010). At ReShape it struck me that support was seen as temporary, demonstrating a belief that clients as citizens will move on to fuller lives in time. This long view took clients beyond basic daily need to bigger goals demonstrating the Sustainable Development Goals such as education, employment, relationships, and holidays. On reflection it seems civic dialogue is often deemed either unachievable or beyond a worker's remit, because the sense of hope it requires to speak of the future is easily forgotten in daily practice (Sennet, 2003).

In a society where the narrative about the disabled individual swings on a continuum between saint and sinner, conversations rarely expand to speak of alternative futures where the ableism they face is addressed. I noted that occasionally, civic dialogue was directly opposed where conversations between workers polarised between technicality and enabling opportunity as a team. There were those wanting to stay within the safety of folding towels and others keen to introduce more interesting activities and new experiences that would challenge clients and broaden their tastes. While recognising that both are important in support work, only the latter speaks to anticipation within a human rights approach. The overall culture was one that allowed time for conversations about long-term possibilities, unlike many other similar organisations I have visited. I experienced this as a demonstration of anticipation, conversation full of hope for an individual's aspirations. Again, the intangible nature of anticipation is highlighted by a conversation in which I was challenged about 'one-page profiles' – documents that summarise an individual's likes and dislikes on a single A4 sheet. As I later agreed, in most typical lives the idea itself would be preposterous. I could not personally summarise what I liked for a week, let alone a year – and what happens next? What does the practice say about the possibility of change for disabled people as a group?

In line with wellbeing literature, storytelling needs to include more stories aiming for engagement, meaning, self-reliance and optimism because they are key to human flourishing (Seligman, 2011; Marmot & Bell, 2012; Pinker, 2014; Marmott, 2015;). Civic dialogue therefore is needed to better articulate an understanding of flourishing as a broader conversation that will secure the societal factors underpinning wellbeing that is deeply interwoven at community level (Layard, 2005; Huppert, Baylis, & Kevene, 2005; Gilbert, 2006, Diener, 2008). Legitimacy based solely on a business narrative, and narrowly focused on the technicalities of need, not only strips down the conversation to one about costs but also helps deny the opportunities disabled people would gain by being seen and listened to in civic spaces. Indeed, their current absence is often read as a truth

supported by a more dominant narrative to which many feel entitled. This is why I think that the disabled population has repeatedly had to fight for rights against never-ending waves that pull them away from having a stronger voice in shared storytelling. A group voice supported by relational networks is repeatedly denied by the individualisation given to each single telling. So often viewed as a ‘few stories’, the many accounts of disabled people’s experience is narrated in ways that strip it of a community and network context – and authoring. This in turn helps deny a recognisable group in a civic dialogue, and their legitimacy as a marginalised group with a voice is rarely acknowledged. The hope in positive expectation needs to be viewed as an opportunity to access a diverse menu for human activity in order to offer a route to long-term flourishing.

7.7 Stepping forward

Reviewing the visit and reflections on it, it struck me that it is ReShape’s web-like organisational structure that stands at odds with those of other services whose structure feeds from a single ‘bucket’: indeed, it has far more impact on culture than might first appear. The short lines of connection in a web, unlike those in the hierarchical tree or triangle, allow for proximity in a structure that reduced barriers often imposed by pyramidal layers. This familiarity, the shape of small, acted as a key to trust by enabling empathy within relationships, because proximity is critical to the recognition of other people’s feelings and encourages a willingness to act in response to people’s feelings – not to our own (de Waal, 2009). The next chapter deals with choosing words to convey the complexity of a shared narrative that supports the empowerment of disabled people discussed here. The opposition to the mainstream narratives cannot be described as counter, as the text telling of the organisation’s culture has many alternative (if often divergent) facets. The storytelling is anti-ableist, not pro-individualist, opposing more commonly agreed themes of injustice than those explored in the web of accountabilities. Yet, while responding specifically to

harmful narratives imposed on disabled people, the chapter speaks to an accountability that would benefit the entire population.

Interlude

The place I chose was unusual, because people there were likely to tell stories that reflected the truths about Jean, not some made up nonsense based on hearsay or society's stories. I observed their working lives, listened to their conversations and got to meet the people they met. I asked questions about their work, the barriers they faced, the help they received and the ideas they used to make sense of their working lives. I watched, I listened and became familiar with their storytelling. I then compared their stories to others, stories in different organisations, tellers at conferences, accounts on the net and in print. I wrote about their ideas, and looked for other storytellers telling similar or alternative stories.

A lot of time and money could be spent adjusting working practice to fix things so that people like Jean suffer less in the organisations they go into. But what about the industries and their policies that influence society? How can discrimination be identified, barriers predicted and injustice prevented? I am sure Jean herself benefits little from acts of generosity to which her gratitude is expected. as the storytelling in the past 2 chapters suggests, going beyond the individual does more to prevent pain – rather than cure harm once its happened. Responding to Jean, therefore, as an individual will always fail to address the cause of inequality, discrimination, prejudice and harm. We all need to address the orthotoxic soup we are steeped in.

In any society where these messages persist, kindness, whether to ourselves or others, is an act of resistance and subversion. (Lothian, 2018, loc 194-19)

Chapter Eight

Words for our worlds!

8.1 The five Ps: Positive, Possible, People, Privilege and Public

In the last chapter, reflections emerging from the visit were explored to tell of a culture that aids the empowerment of disabled clients. In this chapter, I propose five ways of using those aspects of divergence in language – in words and phrases that specifically articulate the ableism imposed on disabled people. The 5 Ps, where each P adds nuance to an aspect of human rights in conversations, are then put together in a conceptualisation of storytelling as craftivism. The extension of radical ideas to the technicality of accountability adds legitimacy to accounts with an intent that resists dimensions of ableist power. Together the Ps articulate a storytelling in which narratives emerge from co-authoring with disabled people, adding their interests as well as their issues to a shared, anti-ableist narrative to disrupt the orthotoxic ones in society more widely. The emphasis on storytelling draws attention to the telling, not the story, bringing about a reality by inviting in authors with a divergent perspective. To paraphrase Freire, the use of disabled people's words is needed – not an insistence that they adopt other people's – to create a new language that more fully respects their experience in storytelling (1970). The stories authored by ReShape's clients have power within and beyond its boundaries to change the wider narratives in society about disabled people. As Schein (2010) explains, where organisational structure and culture come together in a language that supports meaning in everyday lives, values are established and embedded in from the beginning. These values discussed next are those who define human rights alongside a greater vision of emancipation. Approaching disabled people's interests as an investment in the future changes the conversation in and addresses the narratives of injustice. Sergiovanni (2005) defines hope as a wish grounded in reality. Unlike wishful thinking, change rests on a spoken reality – an articulation of real community, capacity, individuality and ambiguity. The five sections below explore different aspects of resistance, rather than the merit of single words that a speaker may use to express the multi-layered characteristics of dis/ableism in culture. I have used 'we' and a more passive tone because it is a conversation of equals, with the third person representing the camera on

us as a group within an organisation or profession. ‘We’ also frames the language within a community of parlance, a shared knowledge gained through co-production (Cahn, 2000; Craig, Mayo, Popple, Shaw, & Taylor, 2011). The paragraphs offer perspectives that, like the shards in a kaleidoscope, shift with movement in ‘a cultural mosaic ... of demographic, geographic and associative groupings’ (Hope-Hailey, Farndale, & Kelliher, 2010, p. 339).

8.2 People matter!

As the tiles in a mosaic, the frames are not shuffled, but placed, to respond to the hierarchy of power described in *tiers of harm* in chapter five. Words and phrases give a richer and more precise vocabulary with which to address layers of prejudice, disablism, ableism, and injustice explored earlier. In the mosaic offered below, each section offers a language to articulate the narratives holding global, local, institutional, organisational, and individual power. At a global level, articulating ableism as an injustice helps place it in the context of a worldwide inequality. At an institutional level, raising ableism in a conversation articulates institutional discrimination that has gone unacknowledged. On a group level, workers or cross-agency networks that articulate ableism in a conversation give new ways of understanding privilege that could benefit disabled and non-disabled clients alike. Finally, at an individual level, articulating ableism places an obligation on the anti-ableist worker to challenge his or her power, thus reducing the potential for unconscious bias. Finally, in the penultimate section, the craft of storytelling is re-presented as an act of activism, with emergent storylines that challenge human rights abuse with strength and fluidity.

8.2.1 Investing in Positive – a global-local language

A language that frames disabled people as a world majority could express inequality more accurately in terms of global scale. Speaking of disabled people as a significant population that is marginalised and therefore positioned against a named oppression of global weight: this is ableism. Naming inequality is a positive shift from understanding disability as a one-off tragedy (framed as individuals failing within the ideologies of consumerism and individualism) to naming ableism as a myth, a perfect standard, an individualism driven by comparison and dulled by consumption (Layard, 2005; James, 2007; Fredrickson & Cline, 2009). While largely unacknowledged, inequality drives a wedge that puts those with complex requirements at one end but also affects many more through *lookism* (Warhurst, van de Broek, Hall, & Nickson, 2009). On a perfect to imperfect continuum, implied failure to reach the desired perfection, is the standard for being fully human (Bourke, 2011). Therefore, having words for a tangible opposition to this desired perfection, hidden within cultural norms, would help state disabled people's humanity in the face of stories about a wider struggle that impact on humanity (Warhurst, van de Broek, Hall, & Nickson, 2009).

A global articulation of inequality allows a shift from understanding disability as personal tragedy imposed on few, to the injustice imposed on a vast number by universal criteria. If 'global inequality' does not seem like an optimistic phrasing, understanding its impact is far more positive in its opposition to orthotoxic ideas that are quasi-immovable. In speaking of the power of inequality, there is resistance to its all-pervasive nature, as words give meaning to the size of the population affected by its impact. At a global level, talking about the impact of inequality on disabled people specifically allows a view of a worldwide crisis (Klein, 2014), framed within the impact of wider societal pressures such as materialism and mass consumption (Wilkinson & Pickett, 2009; Marmot & Bell, 2012; Marmott, 2015).

Inequality is not a new story, as articulated by Marmot, England's Secretary for Health: "Social injustice was killing on a grand scale, with a toxic combination of 'poor social policies and programmes, unfair economic arrangements, and bad politics' being responsible for producing and reinforcing health inequalities" (Marmot & Bell, 2012). It is echoed by the Scottish Chief Medical Officer, Burns, who recalls, "I eventually thought the time had come to stop cutting bits out (of people) and start thinking more creatively about doing something to stop the bits that needed to be cut out" (Hethrington, 2014). Conceptualising larger pressures is complex and discordant, but left silent they remain oppressive for some and deathly for those they oppress (Kahneman, 2011). Therefore an articulation of global scale is important for storytelling because it makes ableism a strategic concern, one that lies beyond the short-term aims of operational changes.

Where mainstream storytelling does not state scale, individual accommodation is costly and likely to fail all marginalised groups – not just disabled people – for the impact of society narratives are disproportionately negative. Without an acknowledgement of the global context, more localised debates (on welfare or education for example) will be skewed by a short-sightedness that also blames disabled people for their inability to rise above personal circumstance; for example the omission of claimants stories in reports on the impact of universal credit (Wiggin, 2012; *Telling It As It Is*, 2016). Framing inequality as an global matter, see responsible organisations more willing to address it specifically as a cost, and more likely to act on the harm it imposes. Because, speaking of disabled people's support as an investment and not a cost presents it as an externalit: as taking care of neighbours of the future (*Our Common Futures*, 1987).

A language used to articulate community more fully adds strength to a political dialogue that can be employed across global networks. Framed positively as community, a global language gives a nuanced way of speaking of belonging within the context of citizenship – for example, seeing

relationships as threads securing the connections that transcend geographical and institutional boundaries (Chapman, 2013). The paradigm shift is seismic: adding ‘community’ to a job title does not alter a business narrative that underpins professional purpose. It helps define co-production, a joint creation or activity adding a value to communities that money cannot buy (Diers, 2004; Block, 2008; McKnight & Block, 2010). Much like Chardonnay at its 80s height, co-production has lost its definition, its sparkle and unique character in recent overuse. The ‘co-production’ epithet has been applied everywhere to everything and its characteristics have become lacklustre, bland, and indistinct. When I discovered co-production in conversation with Edgar Cahn, and later in his writings (Cahn, 2000), his ideas were radical. As he explains in relation to timebanking, co-production challenges the power imbalance created by money: in an alternative exchange that is mutually beneficial and based on hours not dollars, the balance restored is more socially just. While the language of co-production can sit beside business narratives, its essential nonfinancial characteristics are key to challenging wider social narratives. Within co-productive relationships, people get far more than help: they have dignity, choice, and the likelihood of relationships that are not an option within paid exchanges. It is these unanticipated outcomes that help form the social fabric underpinning wellbeing (Diers, 2004; Waldinger & Schulz, 2010). Labelled ‘community organising’, ‘local area coordination’ and Asset Based Community Development (ABCD) across the globe, an approach started by McKnight and Alinsky in the US grew into the ABCD Institute at Chicago University. Explaining nongovernmental work within disadvantaged localities, it is defined as the coordination of cooperative efforts carried out by local residents to promote the interests of their community. Within the discipline, co-production has been understood as creating activity that helps secure wellbeing. It requires a different method and approach, one deeply rooted in social justice (McKnight & Block, 2010; Minkler, 2012). The characteristics that define a community language are those of mutual exchange and reflect emancipatory values. It is seen as philosophy more than a theory, because the intent to empower communities ‘to demand more services from

government was not sufficient. Truly empowered communities... are those that identify, connect and utilize their own assets' (Diers, 2004, p. 14). Instead of 'issues' the word 'interest' is used to denote a very different way of perceiving the determinants needed for people to flourish (Minkler, 2012).

Talking about inequality allows a more critical approach to global growth and its harm to all groups marginalised by unsustainable production. Locating an articulation of the negative power that inequality imposes harm on us all. Without acknowledgement of the global context, more localised debates on welfare or education, for example, will be skewed by a false narrative that those receiving support are somehow to blame for cost and therefore the disadvantage they experience. Saying 'the inequality imposed on the disabled population' rather than 'disability', takes the focus of the personal health issue, and articulates disadvantage as a lack of access to the determinants of wellbeing more available to individuals from privileged groups. As Ehrenfeld (2013) proposes, consumerist ideology - a belief in growth as a good measure of human progress - is leading to an acceptance of market narratives that are now implicit in storytelling in the wider world. He suggests that while 'green washing' may lessen our emotional guilt about the unsustainability of world consumption, it also helps obscure the view of the wider inequality and relentless depletion of the Earth's resources. A belief in the rectitude of growth, may not only fuel our desire for perfection, but may also prevent a storytelling articulating the nuances of equity with regard to human rights: dignity and respect. A human rights equity imperative brings us back to the co-productive values of dialogue, and the importance of working on social justice with community organising orientation. As John McKnight is fond of stating, it is not helpful to look at the empty half of a half-full glass: any fool can find deficits, seeing potential in the half-full part is harder but far more positive as communities **always** have them.

As this section has explained, without clearly expressing the silent and critical pressure of inequality it cannot be neutralised, and its negative power is more likely to paralyse both client and worker (de Waal, 2009). More importantly, referring to inequality rather than disability frames it as a shared community interest, not solely brought by identity, but by stress common to all groups denied determinants of wellbeing (Wilkinson, 2005; Pinker, 2014). While the phrasing of this is still hesitant at ReShape, the intent held within a language of radical hospitality shows that in a culture where rights are spoken, the focus will most probably be on the positives.

8.2.2 Investing in Possibility – a language of hope and ambiguity

A public language is needed to speak of the rejection of disabled people's interests as a specific characteristic the discrimination they face in national debates. Found in the narratives of the press and social media, disablism is often implicit in discussions about institutionalisation, for example, hidden within legislation and policy. As Hughes articulates, the impact of welfare debates that hold disabled people as scapegoats to the many while they focus on the vilification of a few, denigrate individuals without impunity (Hughes, 2015; Ryan, 2019). Where those writing policy, without regard to evidence-based knowledge, have influenced debates, narratives can be viewed as misrepresenting the disabled population, and harming the least advantaged (Wilkinson, 2005). A policy failing to articulate disablism, and represents it unknowingly in its accounts has no legitimacy. All too often, storytellers rely on their own assumptions, rather than make public the impact of discrimination in the context of local history (Wiggan, 2012). Budget cuts and payment reforms based on bias and assumptions discriminate further, as exemplified in the implementation of Universal Credit (Telling It As It Is, 2016). Not only do implementation measures deepen poverty, they impede the possibility of escaping it, when the human help needed is removed by new ways of working (Chapman, 2018). In addition to the financial costs, the welfare reforms under successive governments and migration to more technical payment methods have imposed hardship,

according to the National Audit Office: ‘This has led it to often dismiss evidence of claimants’ difficulties and hardship instead of working with these bodies to establish an evidence base for what is actually happening. ... [National Audit Office] doubt it will ever be possible for the Department to measure whether the economic goal of increasing employment has been achieved’ (National Audit Office, 2018).

The possible differs from the positive in its availability, as it demands for existing positive practice to which development is **then** aligned. It is not only an option in current circumstances, but commitment to an alternative path built on what is available. This double-handed intent seems effortless to some, yet impossible to others, who see the absence of existing evidence as proof of alternative choice. Adams & Clarke suggest that ‘anticipation has long been a component of political practice: decolonization, Marxism and feminism all rely on conjuring the possibility of new futures’ (2009, p. 248). Predicting the possible implies anticipation that is key to innovation, because creating something new is different from fixing something broken. In strategic terms, ‘find and fix’ falls short of ‘predict and prevent’. Telling of the public impact of excluding disabled people and ignoring their interests denies people the opportunity to talk of what is possible to change. Speaking of discrimination affirms the pressures disabled people face, but highlights that non-disabled people do not. Naming the weight of institutional discrimination in context, reveals narratives that are often invisible. It is within the reality of toxic cultures that disabled people are often denied their human rights – an entitlement that non-disabled people can take for granted. Localities free of discrimination are not an option in current circumstances, but an alternative path is available to those with hope. As an inexact vision seems preferable to stagnation in the face of unachievable goals, making uncertainty is critical to moving forward. The bigger goal of belonging reuniting love and power, is rearticulated not as a continuum-imposing option but as a fuller characteristic of emancipatory relationships: ‘power in this sense is the drive to achieve one’s

purpose, to get one's job done, to grow... "the drive towards the unity of the separated." (Kahane, 2010, p. 18). Possible scenarios are critical to an articulation of vision (Senge, 2006), and the resistance to cultural oppression imposed on the disabled population at levels where their presence is missing. Speaking to the activism of the disabled people's movement acknowledges legitimate voices that hold power beyond organisational boundaries. Thus, framing change as in line with a possible vision can sharpen the intent behind even the smallest actions taken within organisations. Viewing a response to the interests of the disabled population as a route to gain is also a resistance to the commodification of their care within a service-led economy. Seeking a possible solution with a positive direction speaks to a strategic intent to promote change for the wider good of society.

In a culture that celebrates what it has (i.e. people's strengths), the negative stereotypes a group might be thought to possess are eroded by a personal experience of difference (Gladwell, 2008). The metaphor can be scaled up or down, and looking for strengths or gifts in individuals, groups and organisations is transformative (McKnight & Block, 2010). Within a population that is already erased in much public dialogue, telling a story of what is possible may change understanding in order to plan different outcomes later on.

However, in its authoring the storytelling has to be sufficiently divergent from the likeability of individuals identified in the personal narratives explored earlier.



Figure 8.1 community capacity

As stated previously, in their locality and across borders, debates can become behemoths that are hard to identify. Acting against them is like driving a wrongly wired car, in that every time we switch to autopilot – our unconscious bias - the vehicle goes off the road.

The language at ReShape shows us that where possible intent underpins articulation a culture of innovation – including mistakes – exists to celebrate change. If it's possible to counter ableism, it reaffirms that disabled people have no alternative route to health, but independent living in their localities, where innovation-driven policy *also* delivers on a commitment to change society legitimately. In contrast to current policy, the storytelling I observed at ReShape was fluid and articulated the conflicting and divergent stories told within it, without eroding uncomfortable truths by smoothing jagged edges. This suggest that in public, talking about ableism as an oppression akin to racism and sexism acknowledges its reality against which a safe space within the organisation can be identified where it is not denied, but understood. Thus, set against wider society, the language is a powerful invitation to experience a safe space. Working on what is reality – the possible – supplies its own energy. As the wellbeing literature indicates, Broaden-and-Building on existing success brings emotion in the short term which is key to securing change in the long term (Huppert, Baylis, & Kevene, 2005). Understood as happiness, subjective wellbeing in the long term ensures health. However, its determinants are wide and varied, and few require the involvement of health workers (Marmot & Bell, 2012). Although health itself cannot be stored or deferred, positive attitudes can lead to a disposition to new circumstances as altered futures are created out of each and every present moment (Gilbert, 2006; Layard, 2005; Marmott, 2015). Effortless for some, and unreachable for others, the ambiguity of hope demands an anticipatory attitude towards a more positive storytelling about the future.

8.2.3 Investing in a Professional community – mediating boundaries

Clients are entitled to hear a language in workplaces that articulates human rights, which unlike the debates stripped to continuums in section 4.3.2, turn the discrimination disabled people face into a public concern. A language is needed for workers to voice the ableism, discrimination, disadvantage and impairment they need to be addressing [since 1999 according to legislation]. Furthermore, in talking solely of money and placing rectitude in figures not the interests of disabled people, working conversation seems to avoid legitimacy altogether. As Sennet states, by making the needs of a group the remit of government provision, not only serves to curtail personal choice, but makes the right to employment, transport, education etc. – the interest – a matter of business; this commodification is ‘experienced that peculiar lack of respect that consists of not being seen, not being accounted for as full human beings’ (Sennet, 2003, p. 13).

Working language overly dominated by a business narrative focused on cost can give the impression that it is the individual’s failure to fit within institutional practices and procedures (Minkler, 2012), an idea further reinforced by the acres of print in positive psychology sold to those wanting to buy happiness (Sang, 2017). This migration of a business narrative into conversations that need to interrogate civic and state accountability is dangerous for all, but particularly for disabled individuals who are already absent from many the spaces where these conversations happen. Denied fair access to education, transport, politics as social activity, means disabled people have little or no voice in the type of conversations that could resist the domestication of business narratives outside their field.

From this perspective, innovation in the development of working knowledge hinges on the positive emotions discussed above, and they may ensure learning extends to envisaging alternative paths. When professionals are happy they are more likely to take risks, be open to new experiences and

feel optimistic about new outcomes: this in turn will aid others towards achieving future goals (Fredrikson cited in Huppert, Baylis, & Kevene, 2005). The Broaden-and-Build effect not only helps explain why clients' lives improve with the right support, but may also reveal why clients and workers stop trying to reach new goals when they feel unhappy. The ReShape stories demonstrate that getting innovative support and mediating existing language outwith the organisation is far more likely to help people reach beyond their present circumstances and toward better outcomes. It seems that a development approach to clients' lives leads towards a more expansive storytelling about their future.

Furthermore, the characteristics of a business narrative is a language within police, education, health and social services that speaks of plugging gaps or responding to crises, rather than adding to the community action that could help prevent them. This domestication extends far beyond disability specific services, as the following extract from the NHS Confederation report states: 'We need to get away from sectors and siloes – the future is about bringing together professionals and services around local populations' (NHS Confederation). The fact that institutionalisation is so embedded is clear when conference slides need to reinforce:

"our residents live in their home, not our workplace!" [Fieldnotes]

A language at ReShape more in tune with an innovative accent was apparent, for example workers called their clients 'people we work for', which helped them avoid speaking of clients as buyers. The limited articulation of disabled people as citizens, the disability specific aspect of this domestication, is that disabled people get talked into playing the role of buyers, or worse – recipients of more successful earners' benevolence. By playing into the 'charity' model, disabled people 'are made to appear unduly dependent and donors further solidify their own social value as able benefactors' (Snyder & Mitchell, 2006, p.41).

For workers in paid roles a business narrative can provide a shield to emotional engagement, and strip conversations of the aspects of life that actually matter to clients. As suggested by Martin (cited in Munro, 1998), this effacement is most prevalent when technical skills take precedence over the emotional impact (in other words, when we can no longer see the faces of those impacted by our actions). I observed that workers used non-technical terms in the conversations where they had power. It made the power they held in a paid role seemed less oppressive. Mediating power, or rather responding empathically, relies on actually seeing the person language has an impact on. As de Waal explains, ‘another’s emotion arouses our own emotions, and from there we go on constructing a more advanced understanding of the other’s situation’ (de Waal, 2009, p. 71). In speaking about what matters to clients, face-to-face contact appears to matter far more in securing the route to wellbeing than simply reducing isolation (Pinker, 2014).

As discussed above, a business narrative tends to focus on needs – the gap to be filled by paid activity (McKnight & Block, 2010). The workers I observed were going into people’s homes and used a non-business language to talk about their wellbeing and what matter to them. In conversation they reframed their own language: this focus on the multiple aspects of human rights no doubt shielded clients from the scarcity narratives driven by concerns for austerity more widely. What I witnessed was a hugely skilled modulation, akin to convergence – adopting another’s language – that ‘is based on the premise that people are mainly seeking to show solidarity by changing their patterns of speech to fit more closely with those of the person they happen to be talking to’ (Thomas, Wareing, Singh, Stillwell Peccei, & Jones, 1999, p. 169). Workers understood the reality of budget cuts, but also mediated the impact of these, by not imposing the blame on their clients. At ReShape the conversations reflected innovative working practice, a paradigm shift from conventional ‘disability’ services, away from a language typically used to articulate growing cost in the sector which it sits.

8.2.4 Investing in People - not budgets

Where sufficiency is wrongly equated to wellbeing, a fuller articulation of satisfaction is required in a financial dialogue that otherwise strips budgets to a bare minimum and threatens long-term health. A simplistic storytelling affords unearned privilege to those less hindered by disadvantage, and denies humanity to those facing most discrimination and inequality. Following the articulation in the web of accountabilities of a financial dialogue that speaks to wellbeing, and not solely survival, we need a fuller conversation about the indivisibility of human rights. A wider focus on the impact of money is imperative within a financial dialogue that stretches the focus on budget cuts. For more widely, in times of austerity those organisations whose services support the independent living of disabled people are put under great pressure to be accountable to funders, which limits opportunities for social interaction and puts more pressure on families (Aikaterini Malli, Sams, Forrest, Murphy, & Henwood, 2018). Where local providers can no longer maintain services in a way that upholds the wellbeing of the people they serve, this may make them less accountable to the specific group they have a duty to support. Larger national organisations are likely to step in. This has two consequences: firstly, larger services are likely to disregard personalised preference - equality of experience - because of economies of scale and detachment due to distance. Secondly, they may be less likely to use local knowledge to make use of the social capital and relational interdependence that favours belonging and flourishing. While it is easier for larger organisations to disregard the breadth of political and human rights agenda, standardisation threatens the choices that characterise a personalisation philosophy. This ensuing mission drift from the respect of individuality to the commodification of individualist care not only threatens wellbeing but more acutely spells *crisis* for the so-called ‘care’ sector across the over-developed world. It is the *articulation* of scale that is important for policy.

Let us not underestimate the harm done to people viewed as ‘less human’. A number of cases have appeared in the media recently concerning the deaths of disabled people in residential facilities. These cases have been unbearable to follow, most significantly I think, because of the way professionals speaking on behalf of large organisations have dealt with the private grief of families. On the other hand, professionals have imposed boundaries, imposing a shield to prevent personal attacks or individual blame, while on the other hand paradoxically overstepping the personal sensitivities of family members. This abuse of professional power, an expression of deeply rooted in institutional ableism, shows the extent of acceptable violence tolerated towards disabled individuals and their families. The words ‘difficult’ and ‘challenging’ are used to describe the field, the families and individuals, thereby placing the problem in individuals not organisations, institutions and society. The impact of institutionalisation is often striking in its use of bureaucratic language to tell stories of human existence - often tragedies - found within the walls of facilities, as if, hiding behind technical jargon, professionals can efface the torture of vulnerable individuals stripped of what they need to live well: kindness, respect, and participation. Steve Broach, a barrister at Monckton Chambers, makes this clear in his blog on the subject of recent tribunals:

‘When Panorama exposed Winterbourne View, a human rights expert described the treatment filmed as ‘torture’... inhuman and degrading treatment and must be labelled as such.’ Only judges and treaty bodies get to decide that human rights have been breached... thereby prohibited by Article 3 of the European Convention on Human Rights. (Broach, 2018)

A notion that re-emerges in every case is the definition of personalisation, and with it the understanding of informed choice. Perhaps the finest articulation I found during this intervention was the blog by Dimensions director, Steve Scown. He stresses the typical balance between ‘important to’ and ‘important for’ which gets eroded by institutional practices that impinge on the way we reach personal understanding and make our choices (Scown, 2018). What is significant about his articulation is that knowing the distinction between what is important for and to an individual is key to making the important decisions affecting their lives – even when this is ignored

in the choice of chips. Secondly, he states the importance of other people in acquiring knowledge, thereby acknowledging the interdependence people seek in decision making - whether disabled or not.

Wellbeing has been used to signify the long-lasting impact of daily happiness, moreover the resilience or decline imposed by present day emotion (Layard, 2005; Diener, 2008; Huppert, Baylis, & Kevene, 2005). The relative understanding of happiness is relevant to the notion of satisfaction, and is critical here. Globally, for example, Portugal is the country in which money stops increasing happiness. For money to make a difference, needs must be fulfilled, but once basic needs are met extra money does not lead to greater happiness. Indeed, some say it may lower daily satisfaction as it encourages the addictive habits of materialism (Gilbert, 2006; James, 2007). Therefore, it seems important to state the long-term and cumulative effect on resilience of a lack of control and a reduced sense of ease (Fredrickson, cited in Huppert, Baylis, & Kevene, 2005). For example, avoiding the bias in assumptions that people with physical impairments are privileged, and therefore responsible for their small advantage, when they are only comparatively less worse off than people with learning difficulties as compared to the non-disabled population. Being subject to a named oppression is still a more difficult position for those facing dis/ableism than those not.

A financial dialogue that enables control, and allows choice, not only interrupts bucket-speak imposed homogeneity by service-led provision but also assures space, is sought for shared activity and the fragile fabric of mutuality where interest can flourish. When applied to the worker/client relationships, on which trust needs to build, it can deny the individuality of members of a group. Positive emotions towards the diversity of humankind helps to ensure that individuality is fully honoured and accepted (Huppert, Baylis, & Kevene, 2005). A language supporting personal choice and articulating individualism also interrupts the internalised oppression that disabled individuals

can struggle with: since people cannot imagine a different feeling while experiencing something else, those who feel miserable cannot anticipate anything but misery (Gilbert, 2006). When individuality is respected and people are happy, they are more likely to take risks. They are open to new experiences and feel optimistic about new outcomes, and this in turn will help them achieve future goals (Fredrikson cited in Huppert, Baylis, & Kevene, 2005). This Broaden-and-Build effect may help explain why ReShape clients' journeys are likely to result in their ever-reducing needs for support, and why organisations that continually ask people what they cannot do – to legitimate bucket spending – end up with people so institutionalised they give up trying to reach goals, let alone plan new ones.

8.2.5 Investing in Public – a shared stewardship

Speaking to ableism needs to happen in line with a civic dialogue placing stewardship as leadership activity within a legitimate storytelling (Block, 2013). While not stepping into a private space that would step over personal boundaries, there is scope within many worker-client conversations to articulate identity without imposing a bias based on likeability and the rejection of individuality imposed by the political narrative discussed above. This will lead to an appreciation that many disabled people are empowered by the stories of the disabled people's movement, and the social model of disability in particular. Setting an individual telling within the storytelling of a group motivated by interest is often a source of power. As Freire states in his call to liberation: 'true solidarity with the oppressed means fighting at their side to transform the objective reality which made them these "beings for another"' (Freire, 1970, p. 31).

More hard-core disability activists have held tight to their reading of the social model of disability as a counter dis/ableist narrative without regard to impairment, to the extent of sometimes losing the person to the theory. A middle ground observes an acknowledgement for at least five conversations,

so as not to disregard the relationship between the individual and society. As Lennard states in his critique of Shakespeare's updated text *Disability rights and wrongs revisited*: 'Chronic illnesses, multiple impairments, pain and the like cause people to be 'disabled' by society and by their bodies and minds'. The statement, while innocuous to those unfamiliar with the issues dealt with so far, is clearly a gauntlet thrown down to defy the notion that disability is entirely an experience of environmental barriers. Rather, there is a cumulative injustice imposed by lack of trust at research, professional and personal levels: it indicates successive levels of harm through the addition of disablism, and ableism to impairment - as articulated by the intersectional approach discussed in section 2.3.

The options are not an 'either/or' proposition, but a imperative to add 'and' 'and' 'and' to conversations: the problem remains that in addition to the ignorance or rejection of the social model, the *being* aspects of impairment - including pain and suffering – are further omitted from storytelling altogether (Davis; 2015). This means that in order to be accountable, workers will need to become fluent in conflicting and divergent narratives, aiming to honour many truths in a complex and nuanced story. Furthermore for those disabled people facing sexism, racism, homophobia, classism, religious intolerance, ageism, and young people's oppression, the disadvantage is cumulative because the impact is multiple. Therefore a multifaceted understanding of stories and tellers needs adding to honour the storytelling of other groups. It is not as simple as defining the 'disabled' against 'abled' (hear post-humanists rejoice!) but a reinterpretation of what intersectionality means when acknowledging where disabled people *already should* belong.

As a first step, adopting self-referencing language (as introduced in basic disability equality) might serve us better than the diffabled, disabled, handicappable nonsense often shared in media across the world-wide web. Addressing the ableism as a resistance to orthodoxy is what is fundamental. It

is only by speaking the name of the oppression that we acknowledge it – even when we cannot take action alter it. Despite recent usage of “ableist!” in *Emmerdale*, accountability to the disabled population through speech needs to become fluent, routine and mundane, in order to be seen as critically important to all. Furthermore, to noticeably facilitate disabled people’s everyday lives in and across public and private spaces, audiences need to see the nuances of disability by giving *ableist* currency of as a recognisable term to establish recognition (Liddiard, 2018). It seems that to claim legitimacy, organisations may need to start looking at disability equality to address culture, the language of the disabled people’s movement to address working terminology.

As the ReShape visit tells, human rights are far more likely to be honoured where personal accountability is encouraged. It is ironic therefore, that the recent euphemism, ‘vulnerable’, is often used to describe individuals from marginalised groups without articulating any reference to the characteristics of the stereotype-driven discrimination, prejudice and oppression they might face. This example of euphemism drift (Robinson, 2009), serves only to hide disadvantage in homogeneity. Furthermore, it entrenches ideas of personal deficit and reinforces the view that some individuals are faulty and in need of a cure – not support. Investing in governance and adding a leadership activity with legitimacy may reduce the unwitting prejudice led by unintended assumptions in our daily conversations. More specifically as advocates, when acting as writers of another group’s story and with the respect for citizenship observed earlier (7.2), it takes conscientious re-articulation to re-present a shared narrative that is emancipatory in direction. Storytelling needs be fluid enough to articulate the sometimes conflicting and divergent stories told more widely, without eroding uncomfortable truths by knocking off the jagged edges. This means being clear that the people within our services do not need to be better clients: it is we as professionals who need to understand that we are stepping out of our world(s) to meet them as full citizens in theirs. It is *their* words we must use, not demand that they adopt ours, in order to respect

their storytelling (Freire, 1970).

8.3 Account-telling as craftivism

“Craftivism is the practice of engaged creativity, especially regarding political or social causes. By using their creative energy to help make the world a better place, craftivists help bring about positive change via personalized activism. Craftivism allows practitioners to customize their particular skills to address particular causes.” Betsy Greer, craftivism.com (Cited in Lothian, 2018, loc 234-235)

The repositioning of disabled people’s rights as an investment for society rather than an organisational or institutional cost presents the activism of storytelling as an externality that can be equated to care for our future selves. Rather than the idea of an ever-increasing cost shouted through austerity narratives, addressing the drivers of ableism could be seen as a move towards a *reduction* in global cost. Told thus, organisational accounts may speak more responsibly and legitimately in their narratives by extending a dialogue about their accountability to disabled people as a marginalised group. It seems the articulation of ableism is important for storytelling because technicality alone fails to tell of what is silenced, and what threatens our common wellbeing in spelling out a *crisis* for society. By staying silent, the storytelling reinforces the ableism to which we are all subject. Yet the ReShape stories tell us that being responsive to existing injustice is demanding heart work (Hochschild, 2012). Kahneman (2011) argues that rationality is easier to believe in than the slower thinking that demands a challenge to accepted distrust found in culture, the ideology, the bias and the prejudice. Therefore, it is not surprised to observe a tendency to ‘forget’ when emotional strength was weakened - by a busy workload for example or the pressure of external demands (Kahneman, 2011).

To add to technicality, craftsmanship as defined by Sennet, brings together a proficiency to do something well for our own inner self-respect, but also for its own sake; ‘It’s not so much a matter

of getting ahead as of becoming inside' (Sennet, 2003, p. 14). As a recognised art, craft started 130 years ago with John Ruskin, William Morris and the Arts and Craft Movement, an idealised form of skill with political meaning, often thought of as honest, high-quality and fulfilling work that countered mechanisation and capitalism (Corbett, 2019). As the visit shows, workers demonstrated this proficiency in conversations that toggled between numerous languages and stories with a craftsmanship that appeared second nature. Their accountability was implicit, therefore, in the way they explained the limitations, demands, and processes of the system to their clients, instinctively crafting their responses in a language that articulated understanding, empathy and love (de Waal, 2009; Kahane, 2010). Crafting language seemed to shield clients from ideas that workers perceived as harmful, or reframed dialogue in ways that presented affirmation, choice and appreciation. This ability to toggle between now/later, positive/possible, rational/sensitive, operational/strategic defines the storytelling as an activity that helped emancipation. For example, a worker able to speak of a systemic discourse in ways that families understand not only expresses care, but offers possibilities for choice. Equally, limiting options for a client who was painfully overwhelmed by the pressure of choice demonstrated a willingness to minimise pain by changing the conversation. This level of craftsmanship in disability services is often missing, as the findings of the investigation into the death of Nico Reed suggests: "All the professionals involved in the planning and delivery of Nico's services should have listened to his family who knew him best. His family should not have been placed in the position where they felt ignored and perceived as 'difficult' whilst advocating what they knew was best for their son' (Johnstone & Duncan, 2018, p. 135).

In each 'P' for investment is a wording that quite intentionally speaks against ableism as a cost to society – not disabled people. By speaking to the Five Ps in storytelling, power is returned to the disabled population, because their interests are voiced, defined by the authority of the disabled population as a civil movement for rights. Viewed as craftivism, disabled people are tellers, authors

of a *distory*, a storytelling that can be blended to address the social and environmental issues that impacts on to world. By its humanity, this call for storytelling may help tackle a disengagement that is largely physiological. As Kahneman tells it, ‘a puzzling limitation of our mind: our excessive confidence in what we believe we know, and our apparent inability to acknowledge the full extent of our ignorance and the uncertainty of the world we live in. We are prone to overestimate how much we understand’ (2011, loc 269).

More specifically, Betsy Greer defined craftivism as ‘a way of looking at life where voicing opinions through creativity makes your voice stronger, your compassion deeper’ (Corbett, 2019, p. 179). Elsewhere craftivism is defined as ‘a form of activism, typically incorporating elements



Figure 8.2 Craftivism

of anti-capitalism, environmentalism, solidarity, or third-wave feminism, that is centered on practices of craft” (Geere, 2014); or in the chapter, *Smells like Craft Spirit: Hope, Optimism, and Sellout in Perfumery* [had to share that title] as “guerilla knitting” or “indie craft” reflect a “new energy” and willingness to re-engage with traditional crafts to protest and critique capitalism, exploitative labour practices and ways of living (Blundel, 2018).

Lothian speaks of craftivism as a voice of resistance, a non-threatening form of

activism that gives people a voice when they feel voiceless and power where they feel powerless, which is now an international movement (2018). Corbett describes how she found the word craftivism by searching the web for ‘craft’ and ‘activism’ to see if there were any people combining the two (Corbett, 2019, p. 179). As Sarah tweets, intentionality, however small, is far from easy.

In terms of legitimacy, craftivism describes the respect extended to disabled people by going beyond technicality to an art that responds to injustice in its storytelling. The Five Ps rebalance a conversation that could be solely about money and hours. A human rights agenda is thus extended to add legitimacy to the organisational conversation, by bringing in aspects of dialogue to extend its accountability. Furthermore, the Five Ps add the emotion and the contact that keeps humanity at the heart of practice by breaking down a distance that would do little to address ableism. As it has more widely (defined as craftivism), heart work challenges the unsustainable impact of consumption with a gentler narrative, and not the hard attack of a counter narrative. The small scale of craft challenges ideas, while the activism encourages a reshuffle in the mindscape, one that stands strong besides the disempowerment felt in a landscape of increasingly unsatisfied appetites (Sergiovanni, 1985). Craftivism helps tell a different story and in a language that disrupts the repetition of an obsession with consumption that leaves people empty, unhappy and unappreciative. Such is the emotional vacuum described as ‘dehumanising’, in which people experience themselves ‘not as a person but as a powerless entity whose value is wholly determined by the market, *something that is ultimately beyond your control*’ (James, 2007, p. 25).

8.4 Stepping forward

This chapter has aimed to make explicit the meaning behind words that offer a tacit resistance to dis/ableism using dimensions of investment that appear to be the culturally accepted as a norm at ReShape. The Five Ps provide an alternative choice in words and phrases that articulate inequality,

institutional discrimination, privilege and personal choice. The section on craftivism draws the dialogue themes and languages together by returning to the idea of a complementary non-financial accountability (Kamuf, 2007). In this chapter the language proposed may be seen as leadership activity, as the words are chosen to help further enhance and secure the rights of disabled people as a named group and are thereby given space in mainstream conversations about society.

The addition of a divergent voice needs to be seen not a charitable benevolence but as a restitution, based on mutuality. It is reminiscent of Freire's (1970) articulation of a culture of silence, conscientious activism or critical pedagogy. As the wording of this chapter suggests, acts of organisational practice which support the emancipation of disabled people include investing in strategic conversation that are far-reaching, anticipatory, outward looking and stretch evidence-based knowledge beyond existing boundaries. Foremost, the words are authored by disabled people in the sense that they adhere to their interests, with a mutually sustaining intent, and with professionals stepping in and out of personal spaces as visitors, not omnipotent experts. Only by retuning, redefining and refining can a fuller vocabulary manifest its relevance to ableism in a culture evolving day-by-day. As Hines (1988) explains, revenue is only understood as revenue when it is named as a reality. Underlying every word, in naming ableism, ableism *becomes* ableism: we state its shape in order to envisage its truth, and in communicating its power we have an idea on which people can think and act. In speaking words, storytelling constructs an account that gives us the power and makes ableism real, recognisable and refutable.

Trust is rarely an immediate option, and in the face of huge prejudice it sometimes requires time, because knowing peoples' stories is a tricky business. Trust grows over time, until the person can speak of it themselves. 'Respectful language begins with an intention to give what others actually

want. Speaking respectfully does not involve benevolence or guesswork, or giving what feels comfortable in response to a need: 'it is a conversation of mutual benefit' (Chapman, 2013, p. 4).

Interlude

Jean isn't a worker, a researcher or an activist. So while her feelings are trustworthy, they need to be represented in ways that reflect the values of objectivity, honesty, openness, fairness, accountability, and stewardship. Beyond her, storytelling needs to be told a legitimate way that shows the realities of life in its fullness, a complex weave of political, public, innovative, financial and civic interests.

*Texts need to reinforce the idea that testimony like hers need to be trusted, not twisted. To tell us why people like Jean are not taken seriously as authors of their own story. Again, Jean doesn't need to know about such things, whereas the professionals that come into her life have a **duty** to protect her against wider harm.*

The stories perform that uniquely human gift – carrying an idea from one mind to another in complexity and with emotion. Stories conquer death – tell a story about someone well and there he is, returned to life, laughing so hard with his arm around his brother that he can hardly stand.

Philippa Gregory

Chapter Nine

Theorising: an act of wonder

9.1 Travelling theory

This chapter looks at how theory could reflect a more anti-ableist intent to articulate a movement beyond the domain of disability studies. In this example, applied to legitimacy theory, in the explicit and implicit terms of an imaginary social contract. Identified below is a breakdown of trust where reputation lacks any acknowledgement of disabled authors or the interests of the disabled people's movement. This demonstrates a lack of legitimacy in organisational accounts within mainstream storytelling. As other movements have shown, change in society is far from linear or smooth, because a challenge to existing orthodoxy is always viewed as unwelcome by those free to ignore their privilege within its established inequality. As an act of wonder, the language of anti-ableism applied to legitimacy speaks to the enormity of the task. Where full disclosure is understood as legitimating narratives, without trust in the voice of disabled people or a nuanced language to describe the oppression imposed from beyond their experience, an organisation's reputation cannot be told vis-à-vis the disabled population. Without words, ableism is not real or part of a shared narrative that is reciprocal in its storytelling. Its cost, therefore, is invisible to a global society that does not speak of its damage.

Theory needs to inform thinking. As Oswick *et al.* put forward, a radical travelling theory is one that moves beyond its own domain of production to be adopted by existing ones with equal measure. Theory that adopts anti-ableism in its intent, therefore, needs a broad applicability and relatively abstract content; so that it can effectively begin 'a process of repackaging, refining, and repositioning a discourse (or text) that circulates in a particular community for consumption within another community' (2011, p. 323). Where legitimacy theory can be defined as the ability to respond to the disabled people's movement as a civil group it will need to demonstrate an intent to address their interests through dialogue (Deegan & Unerman, 2011). However, so far this equal

blending has failed to emerge, because too few conversations have taken place about the impact of ableism within society, and an expected organisational response to the disabled population.

The specific articulation of evidence-based knowledge as anti-ableist weighting seems important. It not only tells why disability is so often treated as a peripheral issue, but also re-positions shared voice within practice so that authority can be equitably blended in theory. This research does not suggest that a domain is any more ableist than any other, but that a belief in the neutrality of existing theory poses questions about how legitimacy is defined across the board. Where disclosure is used to mean the account given by an organisation to the community it serves, and where ‘communities are understood as groups of people that may or may not be spatially connected but share common interests, concerns or identities’ (World Health Organization). In preceding chapters I have argued that without a specific articulation of ableism, talk of human rights without reference to the injustice disabled people face will be devoid of the clarity that could give the term anti-ableist emancipatory meaning. A simplistic narrative focused on individuals’ impairments will be ineffective at best, and will also reinforce negative stereotypes where used in developing knowledge, practice and policy. It thus makes unlikely any positive impact on the emancipation of disabled people. On the other hand, emphasising an alternative narrative – one driven by the trustworthiness of disability studies and the disabled people’s movement – is a better starting point for an ongoing dialogue that would more explicitly extend legitimacy. For those most affected by ableism, the divergence of new narratives at its very edges provides innovative ideas not usually considered in current organisational purpose or policy development. These rougher edges may better address those most disadvantaged by closest to the edge-of-the-edge – people with learning difficulties, chronic pain and those identifying as neurodiverse, for example.

9.2 Emergent explicit and implicit contracts

Articulating two sides of a social contract (the explicit and implicit) with reference to evidence-based knowledge enables an imagined articulation of the potential of anti-ableist intent. This blending could help state discord and highlight divergence more succinctly, so that legitimacy is extended more specifically with the disabled population. Viewed here as a response-ability, legitimacy is articulated as a willingness to first listen and then act with empathy, in a dialogue that secures shared interest. Thus, it fulfils an organisational *contract* to benefit society as whole, and reputation is secured through an activism sent beyond its boundaries. Using the storytelling, not the story but the tellers as authors, anti-ableism intent also addresses stakeholder theory and the legitimacy gap, by helping to re-imagine the human rights through the interests of the disabled population.

There are many reasons for the disabled population not to trust what can, to date, be viewed as a social contract. As chapter four makes clear, inequality, vilification, institutionalisation, rejection and othering do not help weave a culture in which trust flourishes. In the terms defined by public texts, for example, despite the offer of Disabled People's Organisations to share knowledge, an articulation of dis/ableism in is minimal. This is exemplified by rare reference to the social model of disability, which is not yet fully included in documents that are supposed to strengthen, support, enhance or alter practice. The next sections give documented examples of such failures to address ableism.

9.2.1 Explicit terms of contract

In the language of accounts, those written to imply (if not secure) reciprocity between disabled people, the disabled population and the disabled people's movement, accountability is missing where the phrasing omits or distorts the textual world. At a global scale, for example, reputation built without articulation of inequality fails to speak of oppression when, despite adding 'disability' to documents, the meaning of the word 'disability' omits the impact of unsustainable growth. Instead of talking up and investing in a resolution to the climate crisis, when equated to impairment disabled people are viewed as pariahs for their use of straws. There is little legitimacy in adding words that mask assumptions which go unchallenged in a culture that more widely ignores the existence of the marginalised.

On a national level, while British law states that strategic decisions must have due regard to the 'desirability of reducing socio-economic inequalities' and that there is a legal duty to 'eliminate discrimination and other prohibited conduct' (Equality and Human Rights Commission, 2017), the common misunderstanding that conflates impairment and identity helps categorise disabled people as passive clients, not workers – or citizens. Because within a system where equal treatment is stated as 'regardless of the protected characteristics', these are not defined and therefore fail to express the disadvantage experienced by the group and the struggle imposed on a large population.

Within the workplace, although since 1999, the Disability Discrimination Act has made discrimination an offence under the law. Its character is not defined in terms of ableism, with specific definitions of institutionalised disablism: thus it relies on common a misunderstanding that sees impairment – the deficit - as a mark of an individual's identity. This makes it very difficult for disability discrimination or disability hate crime to be policed, reported or prosecuted.

The good news is human rights budgeting and participatory budgeting are emerging in Scotland as a way of developing areas of investment based on the evidence of what citizens value, before the need in formulation of the budget is calculated (Bynner & Terje, 2018). In determining present and future direction, defining what effectively changes disabled people's lives is critical, as this statement from the Scottish Human Rights Commission articulates:

Government uses the budget in an *effective* manner to realise human rights when its policies, plans and programmes as well as corresponding budgets are carefully designed and implemented to best realise the rights in question. The choice of programmes, for example, should be evidence-based, meaning that they should have been assessed and have been shown to have a positive impact on the realisation of the rights. Budget expenditures are *effective* when that they actually help realise people's rights. (Scottish Human Rights Commission, 2018)

As the Scottish Human Rights Commission suggests, participatory budgeting is 'a particularly striking example ... in which communities have a role in defining what a government's budget—particularly all or part of the capital or development line items of the budget—is spent on... Various of Scotland's initiatives to involve communities in policy, programme and spending decisions amount forms of participatory budgeting' (Blyberg, 2017, p. 18).

It is apparent because 'Disability' is used to mean impairment, oppression and discrimination resulting in conflicting stories in different contexts.

9.2.2 Implicit terms of contract

The situation regarding the implicit terms of a contract with civil movement at its heart is far harder to talk about. The taken-for-granted implicit in culture are much more subtle than mere words can say, and therefore it is harder to expose culture in text or conversation. The terms by which an implicit contract is imagined are rarely spoken. This makes the assumption that disabled people's interests are included a hit-and-miss affair. In terms of changing narratives, as stated earlier "We've

changed the words, but not the conversation!” For ableism to be acknowledged implicitly, it will have to be more clearly stated explicitly until it becomes part of a wider storytelling. And when disabled people are sought trusted as storytellers, to tell stories about their reality, and outrage is thrown at ableism, not the rejection of the voices that tell of them.

The implicit mis-representation in a work context was found in the CIPD magazine stating that: ‘employers reminded tribunals will check if they should have known about disabilities’ (People Management, 2018). Grammar aside, the word *disabilities* here has multiple meanings that again conflate illness with oppression, discrimination, and identity. The employment appeal tribunal ruled that because the employer did not know about the impairment, because employee didn’t ‘consider himself disabled’, they were not at fault. However, while an impairment is not indicator that a person is disabled, because identity is a matter of choice, the disablism was apparent in lack of proactive measures to rid a workplace of discrimination, which is in the public interest. Had anti-ableism informed ruling, the legitimacy of the organisation should rest on its willingness to address barriers and not on its power to draw a disclosure – a private matter. A double-whammy, the case reinforced that the burden was “on the employee to show that they meet each requirement within the [legislative definition of a disability]”. As the article concludes, the financial and emotional cost is on those most likely to be on those disadvantaged by more widely institutional discrimination and global inequality.

While implicit, a lack of fuller narratives on ableism also hides the cost to society in the untold story. As Steve Broach, barrister from Monckton Chambers, makes clear on the subject of the tribunals concerning deaths of people with significant impairments: ‘when abuse is exposed, experts do not describe the treatment as torture, inhuman and degrading. Yet, abuse needs to be spoken about as such, not solely by judges and treaty bodies’ (Broach, Rights in Reality, 2018). Hidden is

the damage imposed by wilful ignorance, as evidence exists, and the abuse leading to human misery such rejection perpetuates (Series, 2017). The impact of silencing, often hidden in accounts by a more explicit language about money, denies the telling of disabled people's pain – the reality of human rights abuse on our streets, a testimony of the shameful existence found within institutional walls. It is as if, hiding behind jargon, institutional reporting can step away from the torture it imposes on individuals often denied basic need.

9.3 Legitimacy and trust

These explicit and implicit failures to name ableism suggest an legitimacy gap in an existing contract. More legitimacy is called for, therefore, for conversations to be extended – within and between domains – to demonstrate a notion of reciprocity organisational accounts. Together, examples suggest that more needs to be said explicitly before use of words become implicit short-hands for the five tiers of harm imposed on disabled individuals. Otherwise, legitimacy cannot be conceived as built on the reputation of a storytelling that is an act of negotiation within a contract defined by dialogic action. Using the storytelling, not the story, as a central element of legitimacy building could address both stakeholder theory and the legitimacy gap, and may help secure greater fairness for the disabled population by describing the *ideals* in corporate disclosure.

While legitimacy is often interpreted as 'be-seen' rather than 'be-done', a human rights intent rests on the dialogue, not solely the telling of the organisation's account. More importantly, the tellers speak a truth that disrupt those established stories in ways that benefits society more equitably than by simply adding the word 'disability' without reference to ableism (Ferguson & Nusbaum, 2012). Articulating ableism adds justice within language, an intent that highlight oppression in specific ways by telling about its layers explicitly. The weighting of evidence-based knowledge, adjusting

for the ableism that underpins testimonial injustice, may in its challenge to existing texts provide movement towards more emancipatory ideals. With the web of accountabilities giving direction to conversations about human rights within a dialogue that broadens scope to include disabled people's interest. By articulating this shared authority more explicitly, storytelling as co-constructed knowledge could hold more legitimacy extending beyond organisations. With storytelling seen as part activism and part craft, it holds a deeper commitment to social and environmental interests within a more nuanced definition of reporting telling of a critical and a strategic intent.

As the ReShape story tells, to articulate reputation proves harder than working to break its confines, because addressing narratives of injustice involves identifying them. Organisational reports rarely account for the ways culture does or does not disrupt the orthotoxicity beyond it – in wider society. As many other organisations demonstrate, accommodating to individual need is far easier than engaging on a strategic level with the injustice that imposes hardship on people's lives more widely. Therefore critically, both accountabilities and legitimacy are needed for reputation to be told in ways that impact on those writing the policies that harm disabled people. Without a more defined and nuanced language expressing the need for more explicit terms, change will be very challenging. So far no organisation treats dis/ablism as a purpose in the same way that organisations like Woman's Aid identify as being feminist, for example, by naming Violence Against Women in their conversations about their purpose, and stating equality in a vision to challenge to sexism. The words given to ableism, the oppression, need to tell of the organisation's opposition to the injustice disabled population face. Even if it is only a confused and fluid notion, words need to speak of the relationship between the organisation and the disabled population. Without an anti-ablest language, leaving accountability a matter of chance, organisations will be unable to challenge disablism or institutional discrimination and societal inequality specifically. This suggests it is far harder to talk

about this element of its purpose as legitimate within accounts made to demonstrate reputation, and to add to society's narratives more widely.

While the ReShape culture shows that familiarity breeds respect and understanding – not contempt (Gladwell, 2008), in a culture that allows for re-imagined possibilities these can become realities (Senge, 2006). Demonstrated by the acceptance of the divergent voices in alternative scenarios, trust relies on wellbeing, as positive emotions aid openness (Huppert, Baylis, & Kevene, 2005). Particularly, between policy and practice, the imperative of securing new realities requires a narratives that transforms 'oughts' into 'cans', following a call to protect, respect and remedy, by stepping away from minimum compliance and fear of prosecution (Ruggie, 2008). Handy (2015) suggests that organisations' need to be taking responsibility for change, by using the circumstances of globe-local socioeconomic instabilities as an opportunity to move on from the status quo. Trust, in its critical importance, is possibly the most implicit and intangible ingredient of culture. The fundamental knot that bonds people to community, to wellbeing, and to justice. When an organisation's culture demonstrates trust, it commits to fulfilling its expectations by delivering on the outcomes in the lives of workers and clients. These requirements, or multiple duties, of expectation and fulfilment seem critical in terms of whether human rights are met and a commitment to justice is satisfied. The good news is that we do not need to look far for strength behind a leap of faith: hope is possible and the storytelling is current and present. Not only do workers need to challenge existing storytelling with new stories authored by tellers with alternative perspective, but they need to demonstrate trust in the disabled people who have been failed by storytelling in the past. Trust needs rebuilding, as do the multiple requirements of evidence-based knowledge, this requires listening as each new voice adds both evidence and wisdom to experience (Hawley, 2012). Trust needs to replace distrust with a willingness to listen to those who hold knowledge. To become implicit, disability studies, the disabled people's movement and disabled

people need to be viewed as one of many identifiable civic groups with recognisable interests, and not as oddities easily ignored – shadows in a void of silence. As stakeholder theory states different ‘stakeholder groups will have different views about how an organisation should conduct its operations, there will be various social contracts 'negotiated' with different stakeholder groups’ (Deegan & Unerman, 2011, p. 348). The financial motives so implicit within business narratives need to be ‘tempered to take account of the moral role of organizations and their enormous social effects on people's lives’ (Deegan & Unerman, 2011, p. 350)

9.4 Stepping forward

In this chapter, the ideals of blended theory are examined against existing failures, in order to identify the terms that prevent a re-imagining that could place disabled people’ interests at its heart. Both in explicit and implicit terms, there is a lack of trust within what can be viewed as a social contract. However, using the weighting of evidence-based knowledge, these examples show us where more explicit language could address ableism culture. The examples provided a lens through which reputation can be evaluated vis-à-vis the disabled population. A reputation that could be gained by a willingness to extend accountabilities in dialogue, finding new ways of working together as storytellers, rather than a story told to justify reputation while dismissing human rights abuse. We cannot aim to ask every disabled person about their needs, wishes and interests, but by finding a language to articulate ableism more fully in practice and policy organisation may go further in tackling the oppression disabled people face, and a belief in their words as storytellers.

Interlude

Jean's wellbeing might be taken seriously where workers can name the injustice she faces. Disabled people as a group have stated their interests, and do not need to agree in order to act in unison as a movement. As activists they demand a different language, nuances that demonstrate the complex articulation of their position in society. They need the conversation to change, and to be trusted as storytellers. With no language to differentiate between Jean's personal experience, the discrimination she endures or the myths in society, how can people address injustice in society? We need more words, new phrases that speak of the harm Jean suffers by name. It is not enough to treat Jean with kindness, speaking with benevolence while gaining from the privilege she will probably never come to experience.

Jean's world is our world, challenging the harm that affects her benefits us all. She has every right to meet workers who understand that challenging structural and societal injustice is part of their work.

'Oh what a tangled web we weave when we first practice to believe'
Lawrence Peter

Chapter Ten

**Nothing about us without us...
... can be with us!**

10.1 Looking back

“We all should know that diversity makes for a rich tapestry, and we must understand that all the threads of the tapestry are equal in value no matter what their color.” Maya Angelou

The story began with a presentation of disabled people as a marginalised group who have been silenced as tellers of their own story, and thus erased in the textual world and storytelling more widely. Chapter One was particularly long because, as an introduction, it had to bring into focus a landscape unfamiliar to many. ReShape was chosen as an empirical site because it has a culture in which disabled people are known. The chapter also explained why the methodology preceded a literature review, as order needed to respond to the absence of textual evidence, while aiming to empower disabled people by addressing ableism from the start. In Chapter Two, lack of trust runs underneath the epistemic injustice imposed on the testimony of disabled people, and is most likely the reason why so much research into their interests has been ignored - if published at all - and why, despite a great amount of evidence-based knowledge, people look for a particular type of one-dimensional narrative. Rejection of disabled people’s authority also explains the limitations imposed of the thesis as an academic form, justifying the lack of peer-reviewed texts referenced, the atypical use of older papers and the addition of other sources such as online blogs, Twitter/Facebook posts and conference reports. Trust captures well what defines legitimacy within narratives and culture, while somewhat intangible, trust is the backbone of the weave, a strength behind the purpose, authenticity, reliability, and authority, without which the following text would have little integrity. In Chapter Three, placing trust in the hands of others was a deciding factor in the choice of methods in the exploration of text and language as sites of culture creation and representation. In Chapter Four, a narrative on human rights is explored through a language policy lens. The chapter seeks to capture the lack of trust in the voice of the disabled population, thus avoiding speaking of the injustice they face and resulting in abuse and denial of their storytelling or entitlement to representation in other stories. Chapter Five provides an idealised ‘web of

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accountabilities’, a manifesto for trust of sorts, five axes in which organisations can qualify engagement through modes of dialogic. The ethnographic narrative in Chapter Six paints a vivid series of snapshots in vignettes of an organisation in which a culture of trust keeps the voice of disabled individuals at the heart of its narratives. In these vignettes, trust emerges as a belief in disabled people as trustworthy storytellers, authors of their own lives. The tone then changes in Chapter Seven, as in the chair, trust facilitated the reflexive process that follows each type of dialogue identified in the web of accountabilities. And in chapter Eight, where the act of wonder that is the theorisation links the narratives of injustice to the web of accountabilities, to furnish legitimacy theory which follows in Chapter Nine. In the final notes, in Chapter Ten, trust helps make sense of the chaos – somewhat. I needed to trust my own head and heart, and leave you with my own thoughts with a degree of courage.

Martin Luther King Jr. was a storyteller: in a 17-minute speech in 1963 later known as “I have a dream”, he told of a vision unarticulated until then. In stating, ‘a state sweltering with the heat of injustice, sweltering with the heat of oppression, will be transformed into an oasis of freedom and justice’, he gave words to a divergent story, and naming racism as an injustice, he told of the oppression against black people and people of colour in the United States. His telling called for change, and foretold decades of civil transformation. In telling a dream, he unites multiple anti-racist groups, by spelling out anticipation and hope. He did not change the world, but he began a journey for others. He did not talk in the business terms of ‘agenda’, ‘concern’, ‘future-proofing’ or ‘going forward’. How, I wonder, might history have honoured the words ‘I have a budget’? The speech did not end racism and unfortunately white privilege persists, but in the storytelling of a vision Martin Luther King Jr as both Black author and teller spoke of the many layers of injustice that sit beyond the direct experience of black people and people of colour. His words told a

divergent tale that questioned the truth in the established myth of white superiority. ‘I have a dream’ became the American civil rights movement’s *cri de cœur*.

Similarly ReShape’s story, and what can be learned from it, may take others on a journey; however there remain a few decades’ work to be done until the world is transformed.

10.2 Soulful leadership: heads, hands and hearts

I have referred to leadership a few times, defining it in section 3.4.5 as an activity (not a position) that avoids an operational find-and-fix approach in favour of a strategic predict-and-prevent one that challenges orthodoxy (Sergiovanni, 1985; Hargeaves, 2005; Senge, 2006; West-Burnham, 2009; Fullan, 2011; Handy, 2015). I am not a fan of giving leadership activity an epithet. To my mind courageous, sustainable, inspiring, transformational, quiet, imperfect, dynamic, fierce... are all a part of a definition of leadership (West-Burnham, 1988; Hargeaves, 2005; Senge, 2006; Brown, 2012). However, I will qualify a leadership activity as action that addresses inequality strategically with an equity imperative, thus reframing dis/ableism by talking up investment to counter narratives of injustice in the interest of disabled people’s empowerment.

Introduced as a state of being whole in the section on the researcher as a participant, Sergiovanni (2009) puts forward the idea of leadership as the congruence of head, heart and hand working as one; in which the head holds the theories of practice and ideas that inspire change; the heart holds belief, hope, values that make up vision; and the hand holds choices, action and ways of working. I name soulful leadership, as every situation in which we are challenged to bring the three together, maybe not easily, or fluently, but with a degree of congruence. To soulful leadership I would add Kahane’s ideas of a balance between power and love, with the purpose of creating new realities;

where ‘Love is the other-acknowledging, other-respecting, other-helping drive that reunites the separated’ (Kahane, 2010, p. 32). I have used this idea of soulful leadership to frame the implications of this research from the perspectives of theory, wisdom and practice. As ‘soulful leadership’ in the interest of brevity, leadership activity aims to increase wellbeing in order to lessen the inequality that harms marginalised groups most.

10.2.1 Contribution to theory: head

To counter ignorance, mindscapes will need challenging in order to put words to the inequality disabled people face. Understanding the orthotoxicity in the world cannot be imagined without the guidance of those it harms. Listening to disabled people as storytellers comes first, because as authors with authority their stories challenge the status quo in all areas of societal interest. At the very least a search to find disabled people’s interests a voiced by Disabled and Deaf People's Organisations may increase fluency, aiding resistance to the oppressive impact of global stories. A case-sensitive disposition, then, may improve a critical gaze on world debates, highlighting those that omit evidence-based knowledge.

Theory development, thus, may be thought of as a co-production of knowledge, explicitly balanced to define its application within methodology as anti-ablest. It is the weighting of personal experience, practitioner wisdom and research evidence relating to the characteristics of narratives of injustice that is needed by those theorising about sustainable development. A more blended approach to theories is called for in order to satisfy numerous perspectives of a systems approach to sustainability. The existing stories, with their myths and stereotypes, obscure the sharp edges and lead to the corralling of overlapping ideas into a toothless domestication (Oswick, Fleming, & Hanlon, 2011). It is the divergent ideas brought by authority, not trimmed of their edges and not

sitting inline with others, which are likely to lead in a storytelling that puts disabled people interests into stories of local and global consequence.

As with similar anti-oppressive ideas – say, feminist or antiracist – blending of knowledge from each domain has required an interrogation of sexist or racist ideas. Hidden within layers of privilege, the assumption that ‘when no harm is intended, no harm is done’ perpetuates injustice felt by groups. Tomorrow’s responsibility will be judged by the articulation of today’s storytelling. With an anti-ableist perspective having transformed the writer’s perspective to extend their domain’s knowledge base. It is with anticipation, that in time, writers who trust disabled people as a group and narrate their voices as authors, will tell stories as equitable representations of shared interest within their adopting disciplines. As the notions of craftivism suggest, our mindscapes need to act as maps, therefore we need to be map-makers in imagine the new territories that reshape our global landscapes (Sergiovanni, Landscapes, mindscapes, and reflective practice in supervision, 1985). To paraphrase Joel Barker incorrectly: activism without action is merely a dream, craft without vision passes the time, only vision with action can lead to world change.

10.2.2 Contribution to work: heart

It was at within ReShape that I found my passion for the research. It was an unsentimental love, a desire for justice I would like to see taken for granted everywhere. To step into an organisation without fear: welcomed, wanted and needed. To be able to observe workers who view their daily activities as a route to ensuring disabled people they work for may belong.

I felt a call to speak ways that many may not understand, because many do not have to. Set against conversations about identity, identifying as anti-ableist was about being able to be recognise and interrupt able-privilege. This is really difficult when identity and group definition merge to offer

little clarity in any argument, let alone a solution. Disability is presently used as a personal identity, an impairment, a social construct and an oppression. Yet arguments rage over who is what, has what, belongs with whom and faces what? And few voices make it into other disciplines holding a political view, rather than a personal statement. We need to be powerful as individuals by using words to describe dis/ableism in all its manifestations with nuance. In the same way as speaking of sexism and/or racism empowers change, the words employed to characterise one group's privilege in relation to another group's disadvantage chip away at its invisible nature. It is a passionate endeavour to hear a narrative stripped of an emotional tone that fosters ideas of inhumanity towards those already on the edge. I would love to be able to come across the enthusiasm I found at ReShape everywhere.

10.2.3 Contribution to practice: hands

Applying evidence-based knowledge to practice demands an authentic respect for the stories told by others, and a trust in the knowledge they convey. Accepting another's authority implies a change to daily routine, an anticipation of new trajectory, and different outcomes. Change can be uncomfortable: expect new narratives that will disrupt others by forming new patterns bringing knock-on effects. The systemic and societal power that sits beyond the organisation will take time to shift, but the organisational language that opposes it is important and should not be equated to the chaos that perpetuates hopelessness. The culture at ReShape suggests that where disabled people are known and individuality is accepted, bias or prejudice is less likely.

The language that speaks of ableism as reality is still not used at ReShape ... yet. The question is: does it have to be? If its language is telling the stories of the organisation's disabled clients with legitimacy, does ReShape need to extend its influence? For some groups, such as women and Black people / people of colour, giving sexism and racism a name has made it easier to articulate within a

frame of greater inequality that weighs on women and Black people from beyond their personal experience.

ReShape demonstrates a willingness to change culture. For example, in conversations where workers have questioned the language they use within identified groups – clients, stakeholders and members. An enthusiasm to demonstrate greater fairness in practice lies in its storytelling, not the story told, but the act of welcoming dissonance, mess and chaos. In an age of instant gratification, gaining insight into the characteristics of any oppression must be accepted as hard and challenging given the layers each different narrative brings. Its activity proves that hard does not mean impossible, any step on a journey is one that secures new responsibility, and begins to create new realities for those once ignored.

10.3 Implications and limitations

Accepting a call to consider disabled people's interests as a reality for domains, practice and workers raises issues of social justice relating to society and the environment. Dismissing the individual is bad enough, but denying the growing strength of an anti-ableist narrative because it is too complex or too complicated, is to ignore an interpretation of oppression that only serves to hurt us all. To prevent the extent of existing human rights abuse, a collective pressure from many areas is needed, one that has recognises disabled people's authority to demand change. Daily anti-ableist activity is akin to moving forward while rubbing your tummy, patting your head and talking about the future. While the different activities addresses diverse priorities, they happen together, as interdependent movements with an overall legitimate intent to account for those marginalised by society

The research was ambitious given the scale of the void, and trying to blend matters of disability, sustainability and accountability was far from straightforward. Not being able to find a textual anchor was initially exciting as it provided interest and motivation, but the work was overwhelming and the stories examined were often upsetting. Initial excitement gave way to despondency, as I got to know how little disabled people have been taken seriously, despite their authentic voice in a growing body of evidence and more representation in society more widely. Further work, and more refinement, would be beneficial on the articulation of evidence-based knowledge.

Across disciplines, researchers may need to do much more than follow a wider trend of ignoring the voice of a movement. Texts dealing with disability more specifically need to aim to do more than reflect society's re-presentations, or pay lip-service to impairment-based definitions, by clarifying distinctions between the terms for personal predicament, social oppression and systemic inequalities that are both generated and deepened by global injustices. A minimum would be to cease reinventing disability from personal experience and ignoring these wider issues, with every new thesis and paper. This does not deny that disability research opens vistas for people with impairments and their allies – people who presently feel alienated by some trends in intersectional approaches and cross disciplinary explorations. The academic boundaries as they are, nonporous and resistant to outside ideas, do not submit to domestication and linear borders. There are opportunities for disability studies researchers to specialise in other domains, to the benefit of other theorists. For social and environmental accounting more specifically, each of these past chapters could provide a starting point for further exploration.

As the thesis suggests, applying evidence-based knowledge to a subject led to a re-evaluation of the topic. Ableism informs a conversation on sustainability, requiring a fuller understanding of human rights and the use of a more nuanced language than currently employed. It does not suggest that a

evangelical use of words is needed, but a deep re-articulation of the knowledge base impacting on culture over time. As with all intersectionality, an interdisciplinary approach is a difficult job, but a necessary one within existing debates that are by nature complex and overarching. Even where the effort has begun, distance is still required to match the extent to which society could ideally travel towards a better world.

10.4 Final threads

The world has changed, but pace is slow. I undertook this research because, as a trustee of 3 organisations I was continually baffled by the lack of reference to the disabled people's movement or disability equality. It struck me as unusual that while people were sometimes fluent in their reference to feminism they had no language for anti-ableism. If you put 10 feminists in a room you would get 10 definitions, but that man on the omnibus could not put words to the toxic nature of his pen. More generally when it comes to the lives of disabled people they remain an unknown for many. Far worse I think, in academic texts, where I had expected disability studies to be referenced, writers often ignored, reinvented, or misrepresented the voice of disabled people.

I came to the topic with a fair bit of evidence, wisdom and experience, however, nothing prepared me for the scale of the findings: the huge injustice so many people endure. Furthermore, the sheer lack of words missing, that make debates that are complex and nuanced skewed and harmful. Everywhere I see disabled activists shut out of conversations about the world, then further discredited by those who refuse to trust their hard earned knowledge. Over the period there has been a marked increase in the visibility of disabled authors, but sadly this has been mostly on social media. In the area of responsible business papers are appearing, but a handful seems too few. It is still far too striking how many people in senior positions are largely unaware of a reality that needs to be told in their boardroom.

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12. Appendices

12.1 information and consent form

Accountability and the emancipation of disabled people

Thank you for agreeing to participate in this research, designed to understand the Accountability and the Empowerment of disabled people. All notes and transcripts will be anonymised to protect the identities of individuals. I anticipate interviews lasting between 40 and 60 minutes, covering accountability, human rights, well-being and Person Centred Planning. Anonymised data from the interviews will be used to inform a number of blogs, papers and the final thesis. This may also inform resulting conference presentations and publications. Data will be securely stored, with raw data only available to me.

Digital notes will be destroyed once the project is complete.

Please note:

1. You may withdraw from the interview at any time without providing an explanation
2. No questions are compulsory; please answer as many as possible. However, if any question causes discomfort, please feel free to move to the next question
3. Any data used in reports or publications will be anonymised to protect your identity and that of the organisation..
4. All data will be securely stored
5. With your permission the interview will be recorded (if relevant)

12.2 Participant information sheet:

I am doing some research to find out about accountability with regard to the human rights of disabled people. This involves viewing their interests as a community – or as a group. While I do not need to identify any specific individual, I think the organisation as of interest because of likelihood that the people it provides support to are defined as disabled people under the law. My main question is whether the voice of the group is recognised and whether their interests are acted upon? I would also like to find out whether it has a political weight in the same way as other civil rights movements. I will be looking for recognition of group interest; by using disability equality theory which defines the group's areas of need / disadvantage. In the same way that the women's movement has feminism, Black and people of colour's movement has critical race theory or the LGBTQ movement has queer theory. Accountability impacts directly on the lives of disabled people receiving support. Because, more widely the practice of care has an ethical dimension that impacts on everyone it is delivered to. As human services are paid for by government they more generally can be viewed as serving both individuals and society. That means they have a duty to serve every citizen equitably, making sure that individuals from marginalised groups are not put at a significant disadvantage. Welfare debates and austerity measures at government level have influenced board conversations - and the thinking of workers in strategic positions within the organisation. In times of austerity those organisations whose services support marginalised groups may be under increasing pressure to be accountable to funders. I am curious as to how much this may make them less accountable to the specific / named constituency they serve. This has policy implications because living with an imp costs £400 more per month; therefore a reduced income for disabled people has a disproportionate impact on their well-being, as even the smallest change can limit control and increase stress, both causing illness and some report death.

I consent to participate in this study

Name

Date

12.3 Interview schedule:

These are open ended questions. There are no right answers. Please feel free to pass, skip, or leave any number until later. You can stop at any time.

I appreciate your time, effort and honesty. Huge thank you.

1. Why does your work matter? To you? And / or people we work for?
2. Does what you do help people make decisions?
3. Does what you do have an impact on disabled people's lives?
4. What do you like about enabling choice for the people we work for?
5. Do you think the way we get funded impacts of the lives of people we work for?
6. How does demands of the job impact on the people we work for?
7. Could we serve people better?
8. Can you make decisions that have a positive impact?
9. How much freedom do you have to do the right thing?
10. What stops you doing what's best?

Again thank you, your time and effort is appreciated!!

[name : email]