

Constructions, perceptions and expectations of being disabled and young

A critical disability perspective

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Abstract

This thesis takes a critical disability studies (CDS) approach to explore the concepts of ‘youth’ and ‘disability’. I ask how normative conceptions of youth and disability impact upon the lives of young disabled people and consider how, as youth and disability researchers, we can position young disabled people as active and politically resilient. I argue that thinking about youth, disability and lived-experiences of disabled youth, can teach us less oppressive ways of conceptualising disability and youth, through the notion of becoming-in-the-world-together (Shildrick, 2009).

The method/ology I employ is transdisciplinary, postconventionalist (Shildrick, 2009) and auto/ethnographic. Following Hughes, Goodley and Davis (2012) I utilise theories as and when I see them fit for my political purpose. The thesis is divided into two sections. *Section One* theorises and contextualises youth and disability; whereas *Section Two* introduces fieldwork and contains three chapters of analysis. There were three contexts to fieldwork. The first two involve using a variety of creative methods to ask two groups of young disabled people in northern England for their utopian, best-ever future world ideas. I call this *The Best-Ever Future Worlds Project*. The third research context is a three month ethnography with young people involved in the Independent Living Movement (ILM) in Iceland. The stories, ideas and theorisations of all these young people help me to question, queer and crip discourses of youth, adult and disability.

Findings highlight the ableism of adulthood and the falsity of conceptualising youth as a time of becoming-independent-adult. I argue it is more useful, inclusive and representative of young people’s lives to consider youth, not as a time of becoming-independent, but a time of expanding networks of interdependency. We see dangerous relationships between disability, youth and sexuality functioning to posit disabled people’s bodies as a) childlike (Johnson, Walmsley, & Wolfe, 2010), b) asexual (Garland-Thomson, 2002; Liddiard, 2012), and c) the property of others, to be subject to intervention (Barton, 1993; McCarthy, 1998). The importance of questioning normative discourses of disability and youth for young disabled people therefore becomes clear. I argue this has to take place both inside and outside academia. Reconceptualising youth and disability requires intersectional approaches to research, transdisciplinary conversations, and the development of spaces in which to be ‘critically young’.

Introduction

Theoretical Perspectives

Introduction

My thesis takes you through my PhD journey of conducting research at the intersection of youth and disability. As hinted at in the title, *Constructions, perceptions and expectations of being disabled and young: A critical disability perspective*, I will not only consider the situation of disabled young people. Rather, I will think-through what it means to ‘be young’, to ‘be disabled’ and to ‘be disabled youth’ using the theoretical tools offered to me by critical disability studies (CDS). The approach I have taken to writing is different from your ‘traditional’ PhD thesis. By outlining my theoretical perspectives in this introduction I justify my approach to writing. I start by addressing what I mean by disability and a CDS perspective. I argue that a CDS approach demands intersectionality. The ambiguity and questioning of queer theory sits well with my intersectional approach to research. Drawing on Gibson-Graham’s (1999) term ‘queer(y)ing’ I outline how an approach that continually queer(y)s ethnography, the process of academic writing, myself, and finally, ethics, leads to the auto/ethnographic, reflexive, postconventionalist (Shildrick, 2009) approach which guides my research.

I begin, however, with a letter. In summer 2011 I was asked in a supervision meeting about my direct style of writing: who is the imagined reader of my thesis? Mulling the question over, I realised my imagined audience was not you (academic/disability scholar/I hope, ally?), but somebody I now know as Mr Reasonable: the figure embodying the problem of adult ableism. I decided I would address Mr Reasonable directly in what I think of as a covering letter. I readdress him periodically as the thesis continues. The covering letter begins to explain why I feel it is important to think about youth and disability together; justifications which are extrapolated over the first four chapters of my thesis. I also use the letter to introduce my research questions. Some of the theories I name in this letter are not fully defined within it, but outlined later in this chapter, or you are directed to where I offer more detailed explanations. If you are not yet sure who I mean by Mr Reasonable, I predict that by the end of the letter you will have brought to mind a few Mr Reasonables of your own. For that, I can only apologise.

Covering letter: Dear Mr. Reasonable

Dear Mr Reasonable,

We come across each other less often than we used to. Engagement in CDS has allowed me to surround myself with a motley crew of unreasonable, non-normative folk. You are still a part of my life, but I try to make our encounters infrequent, and they are generally more indirect. I see you on my television and hear you on my radio. Sadly, my family, friends, colleagues and comrades have increasing numbers of Mr Reasonable stories to tell... but I am lucky enough to keep you distant. You are probably wondering why I am writing to you. I am addressing my thesis to you, Mr Reasonable, and all your Reasonable Friends. In this covering letter I explain, a) what I hope we will learn together through my thesis; b) why I am addressing my thesis to you; and, c) why I think we should be learning through the media of youth and disability.

So who are you, Mr Reasonable? What you are not is the *overtly* nasty person that it is easy to be angry with. In fact, you could be that person I occasionally find myself describing as 'alright really'. But as my thesis continues, we will see that this is dangerous. You live by and do not question 'reasonable' rules. This results in aversive prejudice that is difficult to challenge (Deal, 2007). You attempt (though, I would argue, inevitably fail) to be what Garland-Thomson (2002, 10) calls the 'normate': "the corporeal incarnation of culture's collective, unmarked, normative characteristics". You try to embody the "normative, dominating, unexamined power that underlies the rationality of Eurocentric culture and thought" (Smith, 2004). Yet you do not see that in your attempts to be normative, you are oppressing and restricting the non-normative. I argue throughout my thesis that not questioning the normative leads to dangerous implicit beliefs that hinder the lives of those not meeting up to your normative and normalised standards. Disabled youth are one of these groups. My thesis challenges normativity through and with the lives of disabled youth.

Why youth? Why disability? In short, because I feel the disruptiveness of youth and disability challenge your normative ways of thinking. I will use them to highlight and question your dangerous, but oh so reasonable rules. These rules are not necessarily written laws, but rules that become so engrained that they stand as 'fact' (Deal, 2007;

Stein, 2010). Titchkosky (2000) refers to (untrue) ‘facts’ about disability as ‘official textbooks’ of disability. Textbooks teach us that disability is a tragedy and disabled people are deficient, dependent and burdensome. Disability scholars and activists (including, we will see, my young disabled participants) have and are challenging this engrained falsity. Your reasonable rules result in ‘official textbooks’ about other non-normatives too. ‘Official textbooks’ of women (critiqued by feminists), ‘official textbooks’ of people of colour (critiqued within critical race and postcolonial studies and by anti-race activism) and ‘official textbooks’ of lesbian, gay, bisexual and transgender (LGBT) and queer people (critiqued through queering). I argue throughout my thesis that the day-to-day actions of young people are constantly challenging the ‘official textbook’ of youth, yet, we see in *Chapter One*, there seems little in the way of academic engagement with this textbook. Youth research often focuses on young people’s future endeavours as, it is hoped, normative adults. The first four chapters of my thesis critically and theoretically engage with official textbooks of youth in order to contextualise my thesis. Taking a transdisciplinary approach, I borrow from theorisations of my non-normative comrades to aid my task.

I also come to youth as youth is what I know, youth is what I am, youth is what I have been, youth, you will see in *Chapter One*, is what I thought I should ‘grow out of’ when I began my PhD. But youth is what I am now more than happy to be part of. By the end of this thesis, you will understand what I mean when I urge you to inhabit a culture of critical youth. As a youth I have come across, been frustrated by, disciplined by and not known how to respond to many Mr Reasonables. You are the Reasonable Teacher with your reasonable rules, reasonable exams and reasonable lesson plans. The teacher that believes it is only reasonable to stratify and separate children out from the moment they enter the school grounds; punishing those whom refuse to conform (Davis & Watson, 2001). You are the Reasonable Careers Advisor whose lecture I left on my undergraduate course when she asserted that if we did not ‘speak properly’, dared to utter an ‘erm’ or an ‘um’ in a job interview, we would remain unemployed. You are the Reasonable Academic who told me this was ‘just the way it is’ when I pointed out the ableism of that careers advice. You are the Reasonable Boss that told my Mum she needed to “man up and grow some balls” in order to survive work in the public sector: the workplace will not change to accommodate you, so you must change to accommodate it. You are the Reasonable Landlord, the Reasonable Councillor and the Reasonable Politician that live dogmatically by the reasonable, bureaucratic rules of Western neoliberal individualism

(Titchkosky, 2011). We see in *Chapter Two* that in current political times your cries to ‘be reasonable – we have to draw the line somewhere!’ are heard more loudly, and more harmfully, than ever (Titchkosky, 2012).

We see in *Chapter Three* that you endeavour to embody a commodified ‘youthfulness’. Yet, youth also confuses you; the perceived disruptiveness of youth and disability challenge your reasonable rules. As a threat to your reasonable way of being, you demonise the constituted populations of youth and disability (Slater, 2012b). Using the metaphor of paving stones Chandler (2010) conceptualises disability as the ‘crack’ between stones. I argue in *Chapter Four* that youth could be considered the ‘crack’ between childhood and adulthood. Writing of disability, Chandler says:

“We ignore cracks as we move quickly from one space to the next, swiftly moving from the problem of disability to its solution, from living with pride to living with shame. Cracks can also be wondrous, conjoining two parts separated. So I say, from the body of disability studies and the body of my own experience, let us resist the imperative to move swiftly from one paving stone to the next; let us trip up in the cracks and dwell in the liminal spaces of disability. These trips may be painful and these in-between spaces may be uncomfortable, but we will find that we are not alone in these trips. We know things grow in the cracks, flowers and the like.”

(Chandler, 2010)

“We know things grow in cracks, flowers and the like”, expresses what I argue throughout. The stories of young disabled people, a group wrongly and dangerously constituted as passive and unproductive, need to be shared in order to show us the vivacious, blooming potential of disabled youth. These stories challenge current conceptions of how things should (reasonably) be, to instead think about more enabling ways of becoming-in-the-world-together (Shildrick, 2009). I will argue that disability and youth inhabit similarly liminal spaces, and each proves useful in the theorising of the other. By alerting us to the impossibility of the normate, looking through the lens of disability can help to uncover implicit beliefs around adulthood which restrict more than just disabled youth. Considering what ‘blindness time’ can offer ‘culture standard time’, Michalko (2010) writes that blindness time offers “time for normalcy, to develop self-understanding...and this is fucking cool.” “Fucking cool” is exactly how I would sum up a CDS, intersectional, queer and, critically young way of looking at the world. I take up this intersectional, transdisciplinary perspective throughout my thesis.

In my thesis I theorise through and with the lives of young disabled people, via a host of engagements with queer, feminist, postcolonial and CDS literature, in order to consider the following research questions.

1. What dangers do young disabled people face if normative discourse remains unquestioned?

Exploring question one, I show the timely urgency of questioning normativity for young disabled people, and the dangers they face if we fail to do this. These arguments highlight the need for research question two.

2. How can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient?

Question two is both theoretical and methodological. I define ‘political resilience’ not as something located within an individual but, like Runswick-Cole and Goodley (2013, 67) a relational concept located “in a network of resources including material resources, relationships, identity, bodies and minds, power and control, community participation, community cohesion and social justice”. I begin with the assumption that disabled young people are active and politically resilient. Yet, I argue that disabled youth are dangerously and routinely positioned as passive. I seek ways to reposition disabled youth as active and politically resilient. To address research question two I employ what Hughes, Goodley and Davis (2012) call ‘plunder as method’; stripping theories of “any tasty morsel that can be devoured” (Hughes, et al., 2012, 316) for the political purpose of my thesis. This theoretical experimentation allows me to learn from youth and disability in order to address questions three and four.

3. What can disability and the lived-experiences of young disabled people teach us about youth?

Question three follows others with CDS whom consider the lives of disabled people not as tragic but celebratory. In counter-distinction to the assumption of disability as unproductive and burdensome, I ask what the disability and the lived-experiences of disabled youth can teach us about youth (Shildrick, 2004, 2009). First using disability as a conceptual lens to illuminate the ableism inherent to discourses of youth and adulthood, I turn to consider how the lived-experiences of young disabled people pose alternative and more inclusive ways of conceptualising youth and adulthood. Living at the intersection of youth and disability, young disabled people simultaneously teach us the

importance of challenging engrained and oppressive discourses of disability. Hence, research question four.

4. What can youth and the lived-experiences of young disabled people teach us about disability?

To borrow Titchkosky's (2000) phrase, through my thesis I cast a critical eye over official textbooks of youth and disability. I consider what youth and disability have to learn from one-another. As a Reasonable Person, you try fit neatly into the safe, middle ground of current British neoliberal politics (something you will be hearing a lot more about). I offer you this warning: I will argue throughout that the not-fitter-inners, those inhabiting the liminal spaces that are youth and disability, have a lot of teach you.

Let us learn together, Mr Reasonable. Love and kisses,

Jen x

Over the remainder of this chapter, I outline how the research questions will be addressed. I begin with a definition of disability (or not).

Defining disability (or not)

The first thing to ask when I claim a CDS approach is what I mean by disability. British disability studies (DS) rests upon foundations carved by the Union of the Physically Impaired Against Segregation (UPIAS) and the development of the British social model of disability. The social model separated impairment, a perceived lack of or difference in bodily function, and disability, societal barriers, be these physical or attitudinal, which hinder the lives of disabled people (Oliver, 1990). This was a radical step in disability politics. The 'problem' of disability was removed from disabled people and considered as the product of unequal economic market relations. The social model gave disabled people language to shift disability from a medicalised problem residing within an individual, to a problem of societal injustice. To be a disabled person was to be a person with an impairment who was disabled by society. Disability was hence made an identity to base politics upon, and brought into the world of identity politics (Davis, 2002). British DS grew up alongside this identity politics and activism. The gains made by disabled people through the separation of impairment and disability should not be

underestimated. I both celebrate these political gains and believe that strategic essentialism (Spivak, 1988) continues to play a role in disability movements; an argument I develop throughout my thesis.

For my project, however, a social model definition of disability which considers disability purely as based within society and outside the body is not useful. Firstly, it reifies the ‘fact’ of impairment. “The social model – in spite of its critique of the medical model – actually concedes the body to medicine and understands impairment in terms of medical discourse” (Hughes & Paterson, 1997, 326). To be a ‘disabled person’ is to have restrictions placed upon one by a society that devalues people with impairments; yet, the impairment remains as ‘fact’. Secondly, attention is shifted away from the body. As I discuss in *Chapter Three*, feminist critiques have problematised talk of the body being restricted within DS (Crow, 2012; Morris, 1992, 1998; Thomas, 1999). Shifting the attention away from the body in the early days of disability politics was for good reason. Previous medical focus constructed the disabled body as deficient, in need of intervention, rehabilitation and, ultimately, extermination. Therefore, to remove the gaze from the disabled body, and challenge a disabling society was key to the political struggle of disabled people. Nevertheless, the body and issues of embodiment are important to my research, especially due to their prevalence in discourses surrounding youth (Featherstone, 1982).

As DS evolved, so did approaches to discuss ‘the body’ within it. Some have taken a critical realist perspective to talk about the body (Shakespeare, 2006a; Shakespeare & Watson, 2001). Critical realists maintain the ‘brute fact’ of impairment as biological limitation – whether or not this limitation is important to the individual - and assume the reality of a body untouched by culture (Goodley & Runswick-Cole, 2012a). Sitting with the Nordic Relational Model of disability (Tøssebro, 2004), critical realists see disability as a relational concept between ‘really’ impaired bodies and socio-cultural environments; the mismatch of which restricts possibility (Shakespeare, 2006a). Neither, however, do I find this conception useful. Although it means the body can enter conversation, it maintains the reality of impairment and removes bodies from discourse and culture (Goodley & Runswick-Cole, 2012a). Both social model and critical realist perspectives create disabled/non-disabled dualities which are not helpful to my work (Tregaskis & Goodley, 2005).

Hughes and Patterson (1997), on the other hand, call for a sociology of impairment. Drawing on post-structuralism, they argue we need to consider impairment and the body as part of, rather than separate to, socio-cultural discourse. These arguments resonate. My thesis is about questioning the meanings we give to things, and how this constricts what people can do and be. I consciously use the term 'disability' ambiguously and situate my work within CDS. As Goodley (2011, 157) writes: “while critical disability studies may start with disability, they never end with it”. CDS is an interdisciplinary theoretical endeavour that seeks to capture and interpret the lived experience of disability whilst disturbing traditional conceptions of dis/ability and difference more widely (Campbell, 2009; Goodley, 2011). Campbell (2009) poses that we step back from the academic discussion of disability, removing the gaze from the disabled body, to instead focus upon the construction of ability. In my musings over youth I remain vigilant to ableism and utilise Campbell’s definition of ableism as:

“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.”

(Campbell, 2009, 44)

I argue in *Chapter One* that ‘the corporeal standard’ body is inherently adult. An ableist perspective is an adultist perspective; and an adultist perspective is innately ableist. Ableism and adulthood are therefore integral to any discussions of youth and disability. Furthermore, wrapped up in both are a host of other intersectional identities. To consider difference more widely than just disability, CDS demands intersectionality (Goodley, 2011). Research questions three and four reflect my intersectional approach: what can disability and the lived-experiences of young disabled people teach us about youth? And what can youth and the lived-experiences of young disabled people teach us about disability? I take disability to consider discourses surrounding youth. I also take the phenomena of youth and consider what it tells us about disability. My work sits at the intersection of youth and disability. At no point do I stop at an analysis of disability. It is obvious, yet depressingly routinely denied, that disabled young people are also gendered, sexed, raced, classed beings (Goodley, 2011; Priestley, 2003). Thus, it is imperative for me to take an intersectional approach: considering the axes of gender, sexuality, race, class, and so on. Listening to young disabled participants over *Section Two* supports this assertion.

I therefore adopt what Shildrick (2009) has coined a postconventionalist approach to disability. To adopt a postconventionalist approach is to resist defining disability, instead appreciating it as slippery, fluid, heterogeneous and deeply intersectional (Shildrick, 2009, 3). To define, Shildrick argues, is to normalise rather than destabilise the categories we separate human beings into. At the crux of my thesis is questioning categorisation: be this in relation to disability, age, or other intersectional categories. Shildrick (2009) argues that to identify as ‘differently embodied’ is to be classed as the exception to the norm, rather than as one amongst an infinite number of possibilities. As I argue throughout, youth and disability are both ‘differently embodied’ entities; Others to the mythical able-bodied adult. By not adhering to a strict definition of disability, I have the freedom to use disability to question the mythical norm we are both defined in relation to and encouraged to strive towards (Davis, 2002, 2010), whilst simultaneously contesting the meanings we apply to ‘disability’.

By refusing to pin down disability, however, I am not denying the possibility of either identifying or being constituted as a disabled person, nor the significance disability plays in the lives of disabled people. Rather, I argue that there are infinite different forms of embodiment (Shildrick, 2009), which may at times be uncomfortable or painful, but equally, joyful and liberating (Morris, 1991). Disability and impairment are relational concepts: mediated by social, historical, economic, cultural and political factors (Davis, 2008; Longmore, 2003; Timimi, Gardner, & McCabe, 2010); time (Chandler, 2010; Ferris, 2010; Michalko, 2010; Stein, 2010; Titchkosky, 2007, 2011); and space (Hansen & Philo, 2007; Titchkosky, 2011). Different embodiments alter the way we live in the world but the consequential living is not merely a result of impairment or disability. Numerous factors intersect, influence and bounce off one-another to produce socio-economic and political inequalities (Crenshaw, 1989). The way we live is mediated by, yet not restricted to: our embodied physicalities that alter what our bodies can do (Morris, 1991; Shildrick, 2009); material and environmental factors which prevent or allow us to act in certain ways (Oliver, 1990); messages we are delivered through discourse and culture about what we *should* do and be (Reeve, 2002) in comparison to ‘normal’ and favoured ways of living and being (Davis, 2010); and our own personal agency and resilience (Goodley, 2005) – all fluid factors that change throughout our lives. We rely on heavily loaded frames handed to us through discourse and culture to define what we mean by disability (Gergen, 2008). As a society, we value some forms of

embodiment over others, and have chosen to label some bodies as 'impaired' and gone on to 'disable' these bodies (people) (Davis, 2002; Shildrick, 2009; Wendell, 2010).

Troubling the dominant discourse that disability is tragedy is at the heart of CDS (Barnes, 2003; Goodley, 2011; Oliver, 1990). Drawing on and learning from feminist theory, some have used postconventional de/reconstructive conceptions of disability to argue that far from tragedy, disability offers us all opportunity and possibility (Goodley, 2001; Roets & Goedgeluck, 2007; Shildrick, 2009). Garland-Thomson (2002, 2) suggests that integration and transformation are both key to a feminist-disability project:

“integration suggests achieving parity by fully including that which has been excluded and subordinated. Transformation suggests re-imagining established knowledge and the order of things”. I take this postconventional de/reconstructive position (Roets & Goedgeluck, 2007) to ask what disability as a concept can teach us about youth, child, adulthood, and living in the world together. Put in Garland-Thomson's (2002) words, I first integrate disability into the conceptualisation of and discussions around youth (arguing that they have been overlooked). I then go on to play my (small) part in transforming discourses of youth by re-imagining through and with disability and the lives of young disabled people. I explain the structure of my thesis in the final section of this chapter.

As a fluid concept, I use disability differently at different times during my thesis. If disability is such a slippery concept, how can I do fieldwork with disabled people? I address the issue of recruitment further in *Chapter Five*, but here I again reiterate that by refusing to pin down disability I am not denying the lived-reality of disability or disabled people's lives. Western societies are constructed around binaries: disabled/non-disabled; man/women; straight/gay; good/bad; right/wrong. As Spivak (1988) reminds us, there are times when it is strategically necessary to maintain these categories. As Shildrick (2009, 3) puts it although “their power may be based on an illusion, [...] its operation is all too real. What matters is that we do not mistake the challenge to the *effects* of binary opposition as the limit of what is possible and necessary”. There is a lived reality of 'being disabled' (“its operation is all too real”) and being disabled has consequences (“the *effects* of binary opposition”), but what this means varies from person to person over time and space: our own dis/abled relationships to and with disability will change throughout our lives (Longmore, 2003; Watson, 2002). I aim in this thesis not just to document and challenge the oppression (“the *effects* of binary opposition”) faced by

young disabled people. I rather use disability and youth to rethink our becoming-in-the-world-together: to challenge “the limit of what is possible and necessary” (Shildrick, 2009, 3). As I argue over *Section Two*, however, it is important for both these battles to be happening simultaneously, as part of a wider war against ableist adulthood normativity.

Queer(y)ing

Queer theory allows for a questioning of normativity which makes space for ‘otherwise’ discourses (Shildrick, 2009). I draw on ideas emerging from queer theory throughout my thesis (*Chapter Four* outlines the emergence of queer theory). I use queer as a verb: to queer, to make others think differently, to disrupt the status-quo. Gibson-Graham (1999) uses the term queer(y)ing to describe questioning to seek out possibility and change. Queer(y)ing is an integral part of imagining otherwise with disabled youth, not only when directly considering issues around sexuality, but also in order to “mobilize a productive positivity” (Shildrick, 2009, 149). I outline this further in relation to specific research methods in *Chapter Five*. Now, however, I consider how a queer(y)ing positionality sits with my writing style.

Halberstam (1998, 13) refers to a queer methodology as a scavenger methodology, “that uses different methods to produce information on subjects who have been deliberately or accidentally excluded”. Although not excluded from research per se, disabled youth are rarely included in the more ‘liberating’ academic paradigms, such as the new sociology of childhood and youth subcultural studies, and CDS engagement with youth is similarly rare (Priestley, 2003; Shakespeare, 2006b; Wickenden, 2010). Disabled young people come low down the list of people asked about large-scale possibility and change. The phrase ‘scavenger methodology’ sits with my ‘plundering’ (Hughes, et al., 2012), intersectional approach to research. Research question two asks: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient? The transdisciplinary scavenging of theories is imperative to addressing this question. I explain below that my personal justification for research is its political motivation. Like Hughes et al. (2012, 316) I therefore treat “theory as a resource”. I agree that “any intellectual system or social theory is fair game when it comes to building a case for emancipation or for sharpening the tools that are of value in opposing, discrimination, exclusion and oppression” (Hughes, et al., 2012, 315-316).

Throughout my thesis I call upon theories as and when they are helpful to me. Theories developed as political tools should be deployed as and when necessary. I believe nobody should claim ownership of a particular theory (discussed further in relation to queer theory in *Chapter Four*). The status given to certain theories over others concerns me; ‘academic elitism’ meaning the views of some are valued over others, leaving some sidelined by research processes (considered further in relation to methodology in *Chapter Five*). I value the theorisations of Foucault and Bhabha no more than those of my young disabled participants. If a theory sparks off an idea of my own, I utilise it. To justify this, through my writing I map how this idea came about. If an idea comes to me through the words or actions of friends, family or research participants my approach is much the same. This results in an essay-based style of writing where specific theories are introduced at the time of utilisation (I signpost later to where disciplines and theories are introduced).

Queer(y)ing ethnography

“For us, inquiry is a passionate, embodied, and emotional process as well as an intellectual issue, carried on in the heat (or cool) of our action”

(Roets & Goedgeluck, 2007)

“Yes! This is what it feels like to me! My research has taken me places I never imagined, introduced me to fantastic people, let me think things I never thought I’d think, given me space I never thought I’d have, let me be someone I didn’t know I could be. Research isn’t just about me - expert, naive, whatever - researcher learning about disability and youth. Perhaps it’s egotistical, but for me research has been about me and my relationships with the world around me. My relationships to youth and disability.”

(Research diary, 27th February 2012, after spending time with young disabled activists in Iceland, reading the above paper and drinking hot chocolate in my favourite Reykjavik cafe)

I introduce my fieldwork fully in *Chapter Five* where I explain my ethnographic approach to research with disabled youth. With its roots in cultural anthropology, ethnography is about a researcher immersing herself in a culture to try capture and represent their day-to-day experiences (Atkinson & Hammersley, 1994). I certainly feel immersed in the worlds of youth and disability: both theoretically, through reading and writing, and in an embodied sense, by spending time and building relationships with young disabled people; and the two undoubtedly overlap. It is said that an ethnographer is either making the strange familiar (when the ‘research field’ is the space of an Other);

or rendering the familiar strange (when, for example, practitioners' own working environments become the 'research field'). My intersectional approach to research means neither idiom resonates. I may be considered a young person, yet not a disabled person. Perhaps, or perhaps I am not 'youth'. I am not 'disability'. Youth is familiar, yet disability is strange? Neither does this feel right. My postconventionalist approach questions disability, a questioning that is applied to youth throughout. Without denying my normatively embodied privilege, which at time separates me from my disabled comrades, I do relate to disability: through, with and alongside my disabled friends, family and comrades.

Jackman (2010, 116) queer(y)s what we mean by 'the field' in ethnography, arguing that the "field is as much a social and cultural construction as the identities and practices that commonly concern queer studies scholars." During my fieldwork I built relationships with young disabled people. Further detailed in *Chapter Five*, there were three strands to this. The first two strands were carried out with two groups of young disabled people in the North of England. I asked young disabled people to imagine travelling forward in time, and tell me what they would find if the world had transformed so it was 'just as they liked it'. I termed this section of fieldwork, *The Best-Ever Future Worlds Project*. The third strand involved spending time with young disabled activists leading Iceland's independent living movement (ILM). With this in mind, I wonder what would be considered my 'research field'. My own physical locations, the places I have reflected on my research, have crossed countries. 'A-ha' moments occurring as I drink coffee, talk, swim, walk, dream. Perhaps 'the field' was the physical locations I spent time with participants. Or, as I was asking young disabled people to take me on a journey to their utopian, best-ever future worlds, could we view 'the field' as the future worlds the young people took me to? Did we together craft and explore our own best-ever-future fields? And *together* is key here: I was in no sense an objective researcher, but took part in the imagining process (Goltz, 2009). I feel similarly to Heckert (2010, 48) when he writes that, "my experience of research [...] cannot be fitted neatly into separate boxes with borders between theory and data, storytelling and practice; it has been rhizomatic, anarchic, queer".

I cannot wholly separate the stories of research participants from my own. As is often the case in ethnography, throughout the thesis my stories are intertwined with those of my participants (Denzin, 1998). As Spry (2001, 727) writes: "human experience is chaotic

and messy, requiring a pluralism of discursive and interpretive methods that critically turn texts back upon themselves in the constant emancipation of meaning”. In agreement, I situate my work as a postconventionalist auto/ethnographic project (Spry, 2001), immersed in CDS and sitting at the intersection of youth and disability. Spry (2001, 710) defines autoethnography as “a self-narrative that critiques the situatedness of self with others in social contexts”. CDS, auto/ethnography and queer theory all share a commitment to uncertainty, fluidity and becoming subjects (Adams & Holman Jones, 2011, 10). I believe research is relational (Roets & Goedgeluck, 2007; Tregaskis, 2004; Tregaskis & Goodley, 2005). A queer(y)ing auto/ethnographic approach blurs the boundaries between self and Other (Adams & Holman Jones, 2011; Spry, 2001). Advocates argue that one of the strengths of autoethnography is its tendency to make audiences consider their place within writing (Holman Jones & Adams, 2010; Spry, 2001); inviting them “to engage in the author’s subject matter” (Denzin, 1998, 321). My queer(y)ing methodology includes the stories of audiences, both imagined (you have already met Mr Reasonable, and in *Chapter Two* you witness my imagined conversation with welfare minister, Lord Freud) and lived (the interpretations and stories that will resonate with those who read it). I use my own stories, alongside stories of others, to consider the goings-on at the intersection of youth and disability. I choose the term auto/ethnography with a forward slash, over autoethnography to highlight that the aim of thesis is not to tell my story, but to stress that my story is significant and tangled amongst the stories of others (Ellis, 2007).

I concur with Roets and Geodgeluck (2007) that research is a “passionate, embodied and emotional process”, and one that I am undoubtedly a part of. Both feminist and CDS scholars have argued that ‘scientific’ approaches to research (including ethnography), claiming to be objective, have silenced and added to the oppression of marginalised groups. In denying researcher subjectivity researchers privilege the viewpoint of those already in power (Barnes & Mercer, 1997; Haraway, 1988; Morris, 1992; Oakley, 1981). In feminist ethnographic research, researchers are encouraged to keep a research diary in which they record and critically reflect upon their place within the setting, and their biases, thoughts and feelings about the research process (Schwandt, 1997; Watt, 2007). This adds to and is analysed alongside the researcher’s ‘data’ (Kleinsasser, 2000). The process of qualitative inquiry is emergent (Denzin & Lincoln, 1994): the researcher is taken on a journey, unsure at the beginning where she will end up at the end. Self-reflection must be an iterative and on-going process.

Queer(y)ing writing

I draw on feminist notions of researcher reflexivity (Guillemin & Gillam, 2004). I often refer to my thesis, as opposed to traditional references to the thesis, or, in the case of those working within inclusive or participatory paradigms, our thesis. I do this to reiterate the subjective, but also because although I draw upon inclusive methodologies, I do not consider my research methods truly inclusive or participatory (considered further in *Chapter Five*). Although this thesis allows space for the sharing and development of ideas around youth and disability, I believe the person it will have the biggest influence on is me. My voice is overt throughout. Like Watt (2007), my approach to writing was not a conscious decision resulting from immersion in qualitative theory, but a way to organise my thoughts and not lose track of ideas. I write lots, fairly rapidly, and relate to Richardson (1998, 346) when she says, “I write because I want to find something out. I write in order to learn something that I didn’t know before I wrote it. I was taught, however, as perhaps you were, too, not to write until I knew what I wanted to say, until my points were organized and outlined.” The way I work is probably similar to many researchers. I read stuff and think about stuff. During this time, stuff happens in my life. I hear stories of stuff happening in the lives of my friends. I chat about stuff to people. All of this stuff affects the other stuff, both in terms of the stuff I then choose to do, and the way I think about and conceptualise stuff. I then, and perhaps this is where my writing differs from some more traditionally academic texts, write about this myriad of stuff reflexively, in relation to youth and disability. As a result, my writing it is littered with stories of myself, my friends and my family, moving in, out and through the phenomena of ‘youth’ and ‘disability’. I think of this as a process of ‘writing-to-sort-my-head-out’, or as Kleinsasser (2000) perhaps more coherently puts it: writing to unlearn.

My thesis is therefore structured in a series of essays. It is somewhat structured by time: chapters flow into one-another which reflects my own thought processes over the research period (which are continually shaken about, and built differently, only for the process to begin again). *Section One* is comprised of my own theorising which uses CDS frameworks and the conceptual lenses of youth and disability to think about youth and disability. *Section Two* theorises around the lived-experiences, stories, thoughts and

feelings of young disabled participants. I interweave my own stories and the stories of my participants with a medley of transdisciplinary critical theories demanded by my intersectional approach. It is important, therefore, that I queer(y) not just my approach to research; not just the world around me; not just ‘youth’ and ‘disability’; but also myself.

Queer(y)ing myself

“The autoethnographic means telling a story about how much we – children and parents, researchers and subjects, authors and readers – worry about fitting in, about normal, about being accepted, loved, and valued. The queer means telling a story about being half in and half out of identities, subject positions, and discourses and having the courage to be fluid in a world relentlessly searching for stability and certainty. The reflexive means understanding the way stories change and can change.”

(Adams & Holman Jones, 2011, 114)

After graduating I fairly easily fell into my funded PhD. At the same time many of my friends, along with tens of thousands of other young people were struggling to find work. My Mum and Dad were in the company of many others stressed, overworked and bullied through macho competitive managerial systems in a shrinking UK public sector, eventually leading to unemployment. At the same time disabled people such as my uncle were fighting to receive support and benefits crucial to their quality of life/survival, whilst being scapegoated as burdensome drains on society (Garthwaite, 2011). As outlined further in *Chapter Two*, for many, the UK is not currently an easy place to live. Growing up with my lovely Marxist father I was constantly reminded that “philosophers have interpreted the world, Jen, but the point is to change it”, and it is a sentiment that has stuck. It is unsurprising then that I have felt uneasy in my pleasant reading-chatting-drinking-coffee-travelling-around life as a PhD student.

Part way through writing this thesis I told some friends, my Mum and my brother, that I was having a relationship with a girl. From my teenage years onwards I have felt hemmed in by questions around my continued un-coupled status: “have you got a boyfriend?”, “have you got a boyfriend yet?”, “*when* will you get a boyfriend?”, “will you *ever* get a boyfriend??” To Mum’s credit, she never asked, yet I could see her ears prick up at any mention of a boy’s name: “Tom? Who’s he? Is he nice?” My discomfort with these questions was not so much because of the heterosexual expectation, or a desire to be with a girl, but more, as participants in Goltz’s (2009, 574) study put it, the “you complete me syndrome”: I felt I ‘should’, like my brothers, be coupled with *somebody*.

When I was 15 my best mate ‘came out’ to me in a German class. “Jen, I need to tell you something”, Paul whispered. “What?” I replied, “I’m gay”. I was not particularly shocked and do not remember my response, but I do remember him ‘coming out’ to the chemistry class a few weeks later. It was just before his 16th birthday: “Sixteen Paul, you know what that means?” a lad in the class jibed, “you’ll be legal! That’s unless you’re...”, “yeah, it’s different if you’re gay”, Paul bravely replied. I remember proudly recounting the story to Mum: “I don’t see why people have to ‘come out’ like that, it shouldn’t have to be such a big deal”, Mum replied. It was a big deal though. Another friend, openly gay before Sam’s declaration, was routinely beaten-up for the crime.

Four years later, as an undergraduate CDS student, I was introduced to queer theory. I remember trying to convince my Mum how cool it was. “It’s like, why do we put people in these boxes? Why do you have to be gay or straight? That’s what queer theory’s about. I’ve never thought about it before. You shouldn’t have to declare yourself one thing or the other”. Mum did not seem particularly impressed: “I don’t know, Jen, one day you just fall in love with somebody”. I remember being a bit disappointed by her ‘it’s just common sense’ reaction (though really, queer theory, as my Mum realised, *is* just ‘common sense’). At the age of 23, immersed in various critical theories troubling normativity, and blessed with a brilliantly non-normative family, I was not worried to tell Mum of my new same-gender relationship. Yet, neither was I surprised when she responded, “How long have you known you were gay then?” I explained to her that ‘coming out gay’ was not what I was doing. I just wanted to share with her a relationship that I was excited about. “It’s not about her being a girl; it’s just people, i’nt it?” Mum smiled, “Ohhhh, I knew you’d say that!”

Mum went on to reassure me, “you’re Dad doesn’t care what anybody does”. Knowing my Dad, I know he, like my Mum, doesn’t care what “anybody does”, in terms of sexuality anyway. If I declared I voted Tory, joined the British National Party or enlisted in the army, he and my Mum would care what I did. I later laughed about Mum’s reassurance with my brother: why should Dad care “what anybody does”? Mum’s statement, however, appears reasonable, because people do care “what people do”. People continue to suffer for ‘what they want to do’. These two statements signal that even in my wonderful, ‘liberal’, nothing-but-supportive family, there are expectations and norms around what people should do and be. By asking when I “knew” I was gay,

and assuring me “Dad doesn’t care what anybody does”, the heterosexual expectation emerges through their stalwart attempts to not impose anything (so long as you’re happy).

Exploring stories such as this is where my thesis begins. What expectations do we put on young people growing-up? How do these vary when we consider infinite intersecting factors shaping lives? I share this story because it highlights how my immersion in theory (queer, disability, feminist, and so on) has given me the time and space to consider youth and disability and my place within it. I wonder if without them I would have been able to resist the heterosexual expectation: would I have been able to, wanted to, or considered, coming out ‘not-straight’? Secondly, it highlights the hybridity of identity. When I was 15 and Paul told me he was gay, I never considered that just a few years later my geeky bassoon-playing buddy would be an international drag queen. Neither did I consider that maybe I was ‘not-straight’ either. I do know, however, that my experiences of coming out ‘not-straight’ with the words CDS has given me and the circles it has allowed me access to, were decidedly easier (not a big deal), than for my friends in a big Yorkshire comprehensive school (definitely a big deal). Through my studies, I have been able to, and have *enjoyed* the process of queer(y)ing myself and the world around me. I have been given the opportunity to grow into a queer(y)ing space. Critics have deemed autoethnography a self-indulgent process (Sparkes, 2002), a critique that has not passed me by. Perhaps my enjoyment of this process is why my research feels so self-indulgent.

I am maybe not disability, perhaps on the fringes of youth, and maybe not-straight-but-not-gay-either. If I am honest, I can ‘pass’ as any one of the privileged positions these identities entail (I consider the implications of this ‘passing’ as I continue through my thesis). However, these fluid and between positionalities, along with my other intersecting identities of female, white, PhD student, from Wakefield, Yorkshire, affect how I do research. Researching at the intersection of ‘youth’ and ‘disability’ has been an iterative process: it has had a profound impact on me, which has impacted on how I do my research, which has impacted on me, and so on. Whether or not it is self-indulgent, to not write myself into my thesis would seem not only ‘bad research’, but unethical (Kleinsasser, 2000).

Queer(y)ing ethics

My auto/ethnographical stance brings with it ethical concerns. In sharing my stories, I am also sharing the stories of others (Ellis & Bochner, 2000). I have told you about my friends who cannot find work; my Mum and Dad, uncle and brothers; Tom, Paul, the jibing boy in the chemistry class, and the short-lived female-female relationship. Adams and Holman Jones (2011, 109) ask, “what of the stories we want to tell because they are so important and enraging and courageous and hopeful but don’t because they are not ours – alone – to tell?” I can seek the consent of my participants, yet the partial and connected nature of stories (Ellis, 2007) means that in telling any story, I am going to tread on the stories of others. This is particularly pertinent as many of my research participants have become close friends (Ellis, 2007) (further extrapolated in *Chapter Five*). I feel, however, that the ethical benefits of a queer(y)ing auto/ethnographical approach, outweigh the dilemmas. Importantly, these ethical concerns have forced me to take ethics beyond procedural concerns. Moreover, I follow Etherington (2007) and Guillemin and Gillam (2004) in seeing the sharing of stories as an ethical practice.

Broadly, I would not be using auto/ethnography to conduct my research if the political motivation did not sit with my subjective ethical position: to consider, from the intersection of ‘youth’ and ‘disability’ how we can more inclusively, more *ethically*, become-in-the-world-together (Shildrick, 2009). Ellis (2007) writes of ‘relational ethics’. Closely linked to a feminist ethics of care, relational ethics “recognizes and values mutual respect, dignity, and connectedness between researcher and researched, and between researchers and the communities in which they live and work” (Ellis, 2007, 4). Ellis goes on, “central to relational ethics is the question, “What should I do now?” rather than the statement “This is what you should do now”.” Relational ethics sits with the ambiguous nature of my research: there are no definite answers around how I should conduct research, rather, a constant queer(y)ing of my ethical position is necessary. Emergent research requires an emergent ethical position (Ellis, 2007). A queer(y)ing auto/ethnographic approach means this is done overtly. Worrying about ethics alone and with others has been a constant force in my research: whether it be the ethics of being paid to read books when people around me are struggling to survive; the ethics of writing about, and therefore reifying an already scrutinising gaze on disabled youth (Priestley, 2003); or the ethics of blurring the boundaries between friendships and research (Brooks, 2006; Ellis, 2007; Tillmann-Healy, 2003). All of these worries emerge and are further extrapolated throughout my thesis. Perhaps Josselson is correct, however, when she writes:

“I would worry most if I stopped worrying, stopped suffering for the disjunction that occurs when we try to tell the Other’s story. To be uncomfortable with this work, I think, protects us from going too far. It is with our anxiety, dread, guilt, and shame that we honor our participants. To do this work we must contain these feelings rather than deny, suppress, or rationalize them. We must at least try to be fully aware of what we are doing.”

(Josselson, 1996, 70)

The structure of my thesis

The approach I have set out requires my thesis to take an unconventional, or perhaps postconventional shape. Rather than outline all the theories that I will draw upon now, I call upon theories as and when I need them. I outline where you can find them in relation to specific chapters below, along with where and how I address my research questions. Including this introduction and the final discussion there are ten chapters, which I separate into two broad sections. *Section One: Theorising and Contextualising Youth and Disability* contains *Chapters One to Four*. Here I plot the theoretical landscape and contextualise youth and disability. At the end of *Section One* there is an intermission, where I write again to Mr Reasonable and consider what we have learnt so far. *Chapter Five: Method/ology* introduces my fieldwork and young disabled participants, bringing us into *Section Two Analysis and Synthesis through the Lived-Experiences of Young Disabled People*. Over *Section Two* I engage with data, applying theories and arguments from *Section One* in the three analysis chapters. As my letter to Mr Reasonable shows, my analysis of ‘youth’ was a process that started before I considered beginning a PhD. The analysis of the situation was (and continues to be) an on-going process. I will now further distinguish *Sections One* and *Two*, before going on to detail specific chapters.

Section One has two purposes. Firstly, it contextualises youth, disability and the positioning of young disabled people. Theoretical contextualisation begins in *Chapter One* through engagement with disciplines that have considered youth and disability. Political and policy contextualisation happens in *Chapter Two*. I argue the timely importance of questioning and rethinking youth and disability as I begin to address research question one: what dangers do young disabled people face if normative discourse remains unquestioned? We see young disabled people’s positioning as passive marks them as disposable. Thus I argue the importance of research question two: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient? *Section One* also explains why I believe it is

productive to think of youth and disability together and therefore justifies research questions three and four: what can disability and the lived-experiences of young disabled people teach us about youth? And what can youth and the lived-experiences of young disabled people teach us about disability? The former of these questions I begin to theoretically address in *Section One*, as I use disability as a conceptual lens to highlight the ableism of youth and adulthood. I address the latter two research questions more fully however in *Section Two* through the embodied lived-experiences of young disabled people.

Chapter Five explains my method/ology and approach to analysis, before *Section Two* synthesises *Section One*'s theorisations with data generated through fieldwork. I continue to address research question one; as the lived-experiences of disabled youth 'make real' the dangers young disabled people face if normative discourse remains unquestioned. Again, we see the importance of research question two: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient? Interdisciplinary exploration demanded by this question allows me to share the stories, thoughts and creativity of young disabled participants to highlight their active political engagement. Furthermore, this approach also allows me to rethink youth and disability, thus addressing research questions three and four: what can disability and the lived-experiences of young disabled people teach us about youth? What can youth and the lived-experiences of young disabled people teach us about disability?

Outline of chapters

Chapter One, Playing Grown-up: Interdisciplinary thinking about youth and adulthood sets the theoretical tone. Through critical readings of social scientific literature around youth and disability, I outline a framework which considers constructs of youth under the headings Youth as Passive, Youth for Sale and Youth as Active. CDS is my conceptual lens to interrogate confusing and contradictory representations of youth, and ask where disabled youth fit in. I justify my reasons for considering adulthood within any theorisations of youth. Rather than directly answer any research questions in this chapter I outline the need for further interrogations of youth and disability. An interrogation I continue as I move on to directly address research questions over the remainder of my thesis. A paper based on this chapter is available in *Youth: Responding to Lives—An International Handbook* (Slater, 2013, f.c.).

Chapter Two, Disability and Youth as Passive in British Political Climates

contextualises my research within welfare-cutting neoliberal Britain. In *Chapter One* I highlight that disabled young people are routinely relegated to the realms of Youth as Passive. In *Chapter Two* I ask where those construed as passive are left in a consuming society. This chapter therefore bridges Youth as Passive and Youth for Sale to address research question one: what dangers do young disabled people face if normative discourse remains unquestioned? I consider both academic research and policy documents around young disabled people and I introduce a Foucauldian analysis (also drawn upon in later chapters) to consider rhetoric surrounding disabled youth in relation to cuts to public services in Britain. I outline the urgency of repositioning disabled youth as active and politically engaged. Thus, I justify the importance of research question two: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient? A question I continue to address through transdisciplinary engagement over *Section Two*.

Chapter Three, Youth for Sale and the Aesthetic Project of Youth continues to address research question one: what dangers do young disabled people face if normative discourse remains unquestioned? However, I take a different approach to that of *Chapter Two*. I take a feminist-disability perspective to consider Youth for Sale; a gendered, commodified and abstracted notion of youth I argue we are encouraged to embody, despite age. I consider the potential consequences of Youth for Sale for disabled youth. I follow these arguments up in *Chapter Eight* in relation to the lived-experiences of my young disabled participants. A paper based upon this chapter is available in a special issue of *Societies* called *Embodied Action, Embodied Theory: Understanding the Body in Society* (Slater, 2012c).

Chapter Four, Is Youth Queer? Disability, Youth as Active and Productive Possibility marks a turning point in the thesis as I consider youth and disability as entities of marginality that force us to think otherwise. I outline why I believe it is productive to think about youth and disability alongside one-another. Thus, I extrapolate the thought behind research questions three and four: what can disability and the lived-experiences of young disabled people teach us about youth? And what can youth and the lived-experiences of young disabled people teach us about disability? In this chapter I further discuss distinctions between British DS and CDS. I relate these debates to the emergence

of queer theory. I outline how postcolonial and Deleuzoguattarian theories can help me think-through ‘inbetweenness’ of youth and disability in later analysis chapters.

This concludes the theorising and contextualising *Section One*, the majority of which was thought-through in the first year of my research. I reflect back on what we have learnt over this section, by again addressing Mr Reasonable. The positive possibility of *Chapter Four’s* theorisations feeds us *Chapter Five, Method/ology* in which I introduce my fieldwork with young disabled people in. *Chapter Five* explains the methodological influences of my work, before detailing the actual methods of research and outlining how I approached analysis.

Chapter Six, Disabled Youth as Active; Questioning Youth Culture is the first analysis chapter. It begins with the assertion that young disabled people are routinely denied access to youth cultures (Priestley, 2003). However, rather simply documenting oppression, I engage with youth subcultural studies to question what we mean when we speak of ‘youth culture’. This engagement allows me two avenues. Firstly, engaging with feminist critiques of youth subcultural texts allows me to address research question two, how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient? I show disabled youth actively negotiating time and space within segregated setting, rarely associated with youth culture. Secondly, it allows me to address research questions three: what can disability and the lived-experiences of young disabled people teach us about youth? Disabled youth teach us about the exclusionary nature of youth culture. I pose it could therefore be more productive to think about cultures of critical youth.

Chapter Seven, Disabled Youth Becoming-Independent-Adult: Crippling Youth as Active continues to address research question one: what dangers do young disabled people face if normative discourse remains unquestioned? I consider the lived-consequences of disabled youth being considered outside a discourse of youth as becoming-adult. I find disabled youth challenging disability as a difference in order to fight for their place within normative conceptions of adulthood. Young disabled people address research question four: what can youth and the lived-experiences of young disabled people teach us about disability? Disabled youth teach us that disabled people are “no different from any other person and that we like to be treated equally” (transcript from research contextualised further in *Section Two*). Thinking back to *Chapter Two*, however, I worry

that for young disabled people to assert themselves within normativity is not necessarily a desire, but a mode of survival. Research question three asks what disability and the lived-experiences of young disabled people can teach us about youth. I argue that young disabled people striving to assert themselves as independent-adults crip normative conceptions of adulthood independence. Becoming-adult, young disabled people teach us, is not about doing things on your own, but about increasing and dynamic networks of interdependency. I argue that as disability researchers, we have a responsibility to expand notions of independent adulthood, to relieve disabled youth the pressures of ‘playing grownup’.

Chapter Eight, Disabled Youth, Gender and Sexuality: Crippling Youth for Sale is the final chapter of analysis. Here I re-engage with the concept of Youth for Sale from *Chapter Three* to consider young disabled participants’ thoughts and feelings around disability’s relationship with the body and sexuality. I think about research question one, the dangers young disabled people face if normative discourse remains unquestioned, alongside the lived-experiences of young disabled women. The felt-exclusion of young disabled women from discourses of normative sexuality becomes clear. Engaging in CDS literature, I assess the dangers this exclusion poses to young disabled women. However, I also show young disabled people to be challenging their positioning as asexual, genderless beings (Liddiard, 2011, 2012). I thus address research question four, what can youth and the lived-experiences of young disabled people teach us about disability, as I highlight the importance of including disability in gendered and sexualised discourse.

The final discussion chapter, *Learning from and about youth and disability, and the lived-experiences of young disabled people*, closes my thesis. Here I outline the findings from my research questions, and the implications my thesis has for further research. I argue the importance of developing a culture of critical youth, both inside and outside academia. I maintain spaces of critical youth allow for immediate and necessary identity political fights of disabled youth, but also longer-term battles: rethinking notions of youth, adulthood and disability, in order to appreciate a multiplicity of ways of be/coming. I end my thesis by writing to say goodbye to Mr Reasonable. I explain how I and, I hope, Mr Reasonable, can live by, and therefore disseminate, the convictions of my thesis.

Section One: Theorising and Contextualising Youth and Disability

Chapter One

Playing grownup: interdisciplinary thinking about youth and adulthood

Introduction

This chapter sets the theoretical tone by intertwining the reading I did in the first year of my studies, alongside my own thoughts and feelings as a 22/23-year-old new-to-the-world-of-research definitely-not-grownup. It is based upon feelings expressed in a paper I gave when three months into my PhD. I present the original introduction here as a primer to what follows.

“Shit, this is proper grownup stuff”

After four years as an undergraduate student in Sheffield and a lazy summer with my parents in Wakefield, I moved to begin my PhD in Manchester. Previously living with friends and my big brother, suddenly I have my own flat in a big new city. The title of this chapter, *‘Playing Grownup’*, reflects feelings since the move: “shit, this is proper grownup stuff”. This phrase has numerous times crossed my mind and passed my lips. I distinguish between thinking and speaking because they tell different stories. “Shit, this is proper grownup stuff” emerges as a thought at times of personal reflection. In my flat by myself; panicking because I cannot disable the smoke alarm; remembering how, although I wanted my own place, it was nice to have my big brother in the adjacent room for whisky-fuelled putting-the-world-to-rights conversations. It reflects the new, scary bits of my life: moving to a city where I don’t know anyone, living alone for the first time and feeling like a fraud, like I’ve tricked somebody into letting me do a PhD. When I say it aloud, however, it’s said in jest; acting as an icebreaker, especially if I have to reveal my age. The situation I’m in does seem ridiculous, totally surreal. Dr. Jen? It’s a joke! And, by joking about it, I’m protecting myself, backing myself up, pre-empting what I think you may be thinking – I know I shouldn’t *really* be here, I’m not a real grownup.

Two points need highlighting here. Firstly, when I share this phrase there is no precursor needed; there is shared cultural understanding as to what it means to be ‘grownup’. We

all ‘get’ the joke. Through our laughter, we agree that some part of my current situation is more ‘grownup’ than previously. Secondly, the phrase reveals my personal insecurities about this ‘more grownup’ status. The worry being that others will consider me a fraudulent adult: too young, a baby. McRuer (2006) makes the connection between disabled people ‘passing’ as non-disabled and queer people ‘passing’ as heterosexual: at the minute, I feel the need to ‘pass’ as adult. If, as is commonly asserted, youth is a time that precedes adulthood (Wyn & White, 1997), there must be certain benchmarks I can meet to prove myself as adult. What do all these grownups do in their first PhD year? A literature review, I’m told. Great, starting my literature review (researching around youth) can double as developing my strategy of adulthood deception. Jenny Slater, A.K.A. *Hercule Poirot*. While researching around youth I can work out what adults are meant to do and be, and hopefully convincingly fill that role.

Signposting

This chapter uses critical readings of interdisciplinary literature to think-through my youth/adult/not-grownup-enough-to-be-a-PhD-student dilemmas. I begin with a background to developmentalism, theories of which continue to dominate our thinking of child, youth and adult (Burman, 2008a, 2008b). As these theories consider ‘adulthood’ the ‘end point’ of youth, I argue that theorising adulthood is vital to understanding discourses of youth. Research question two asks how disability researchers can share the stories of young disabled people in order to reposition them as active and politically resilient. As outlined in the introductory chapter, addressing this question requires interdisciplinary engagement. I combine literature from CDS, critical studies of youth, youth subcultural studies, youth and community work and critical psychology to consider benchmarks I must meet to be considered ‘adult’. Highlighting the ableism of adulthood discourse, I begin to plot some of my concerns in relation to question one: what dangers do young disabled people face if normative discourse remains unquestioned? Conversely, I find that remaining ‘youthful’ is a key part of being ‘adult’. Finding UK policy-based definitions of youth inconsistent, I turn to consider how youth research has been tackled, and how cultural discourses form our conceptions of ‘youth’. This leads me to develop a framework for exploring youth under the headings Youth as Active, Youth for Sale and Youth as Passive. The remainder of this chapter maps these out in turn, before they are further developed in *Chapters Two to Four*. Although not the sole focus of the chapter, CDS perspectives remain throughout as I use the conceptual lens of disability to critique

discourses of youth and adult. Thus, I begin to reveal the potential of research question three: we see what disability can teach us about youth.

The tyranny of developmentalism

If age is a ‘biological reality’, youth is simply a way of constituting a population based upon this ‘reality’ (Wyn & White, 1997). This was the assumption of many developmental psychologists in the ‘normative period’ of developmentalism (Berk, 2010). Granville Stanley Hall in the late nineteenth century grounded studies in evolutionary ideas, generating norms and averages which he claimed represented ‘typical development’ (Berk, 2010; Burman, 2008a). Hall is perhaps most famous for developing the ‘storm and stress’ model of adolescence. He attempted to explain the (continually) prevailing view of young people as rebellious and irresponsible (Wyn & White, 1997) by arguing that adolescence was a period of neurological turbulence which paralleled human ‘development’ from ‘savages’ into ‘civilised beings’ (Berk, 2010). Piaget took a similarly homogeneous view in the 1930s: his cognitive-development theory suggested a set of universal problem-solving stages which children pass through as they mature to adulthood.

It is not hard to criticise such theories from CDS perspectives: assuming norms ousts those that not fitting these pseudo-categories. Wyn and White (1997) highlight that conceptualising youth as a homogeneous group has been troubled by youth researchers periodically, yet sporadically, over the last 40 years. Allen (1968), for example, argued ‘youth’ is a result of social, cultural, political and historical relations. It would be fictitious to write that developmentalists take a purely biological stance. Piaget saw human adaptation to environments key to development, and the nature/nurture question classically illustrates the biology/society debate. Furthermore, although the majority of early twentieth century development research focused on the time preceding adulthood, more recent lifespan perspectives have considered development a continual process, not ending at adulthood, and allowing for multiple and diverse trajectories of development, influenced by both hereditary and environmental factors (Berk, 2010). Nevertheless, there remains an overriding assumption that development has “universal features” (Berk, 2010, 7) and the job of the developmentalist is unchanged: how to “best describe the differences in capacities among infants, children, adolescents and adults” (Berk, 2010, 6).

Developmentalist ideas influence day-to-day living to become common-sense knowledge (Burman, 2008a). Although there is an acceptance of diversity within age-groups, certain characteristics remain associated with particular age-groups (Berk, 2010). Piaget's stages of cognitive development, for example, reflected in age-based school structures (James, 2000). Furthermore, although there is an appreciation of multiple pathways to adulthood and a discourse of young people making their own future decisions, the choices on offer are limited – and more limited for some than others (Facer, 2011b; Hicks, 2002; Kelly, 2006). Wyn and White summarise the concept of transition as follows:

“The concept of transition, which has the imagery of process, fluidity and change, has been harnessed to a static, categorical notion of youth. Hence, although we appear to be dealing with a concept which has change and process at its centre, it offers instead a perspective on youth as a steady progression through identifiable and predictable stages, to a set end point: adulthood.”

(Wyn & White, 1997, 94)

Wyn and White's (1997) 'harnessed' concept of transition links it with development. Developmental theory, argues Burman (2008b, 35), “makes assumptions about who is more/less developed”, both in terms of individuals meeting certain benchmarks and when considering larger scale phenomena, such as global systems. Development is about change, but changing in the 'right' way. Development is directional. To develop is to progress. The offshoot is that development is based upon norms and allows for slippages: from young person to young people; from the way it is, to the way it should be (Burman, 2008b). Considering youth as transient is to consider young people incomplete-adults, focusing on futures rather than here-and-now experiences. Adulthood is the full stop at the end of youth.

Research question one asks, what dangers do young disabled people face if normative discourse remains unquestioned? From the above, we begin to see the exclusionary nature of normative developmental discourse; arguments developed through my thesis. Now, however, I turn to consider policy definitions of youth.

Defining youth in the UK

If youth is about becoming-adult, at what (st)age does one leave youth and enter adulthood? A definition of 'youth' could help me out in my mission of 'passing' as adult.

As a non-disabled 23-year-old in the UK, although I would have access to some services and schemes aimed at ‘young people’, legally, I left childhood and became an adult five years ago. Policy-based definitions of ‘young person’ are inconsistent, spanning the legal definitions of child and adult. Goodley and Runswick-Cole (2011b) highlight, that definitions of ‘child’ are not straight forward in government policy either: the mother of a ‘disabled child’ hoping to access services, may find their ‘disabled child’ is neither ‘disabled’ nor a ‘child’ in one service, yet fulfils both definitions of another. Leaving childhood and entering adulthood is more complicated than reaching 18. I have failed to find a universal government definition of young person. According to the UK’s *DirectGov* (2011a) website (which compiles information on all government public services):

1. Since my 20th birthday I have been too old to contact a *Connexions Advisor* offering “information, advice and support on a range of issues affecting young people”.
2. I would have to be between 13 and 18 to take part in the *UK Youth Parliament*.
3. Since being 21, I have been eligible to receive full minimum wage.
4. If I was unemployed, I would be in the bracket of young people, aged 18-24, who would be referred to the government’s new ‘*Work Programme*’ after nine months, rather than the statutory 12 months for those 25 or over.
5. Until I reach 25 my car insurance is more expensive than for those 25 and over.
6. Until it was scrapped in March 2010, I was able to access the *A Night Less Ordinary Scheme*, which saw the government subsidising theatre tickets for ‘young people’ aged 26 or under.
7. Since 16, I have been eligible for a *Young Person’s Railcard*, offering me discounted train fares until my 26th birthday.

In government policy it is no longer reputable to slot young people’s needs into age brackets: the Kennedy review of NHS services recommended a move away from offering services based upon birthdays to one based upon individual needs (Department of Health, 2010). Policy makers proclaim that youth is not age-bound, but a stage of life. Nevertheless, there is an expected correlation between the two. One of my first Manchester discoveries was a coffee shop with free refills around the corner from my flat. A group of new mums had discovered the same place, regularly ambling in with their pushchairs to talk ‘baby’. It did not take very much eavesdropping to realise that

these women were more than aware of the targets their babies ‘should’ be hitting (Piaget’s theories in action on the streets – or in the coffee shops of leafy Manchester suburbs, at least). With young people, the targets are not handed out in medical literature, but implicit cultural expectations. Your aim, hooded youth, is to reach adulthood.

Hitting the benchmarks of adulthood

Even if I am legally an adult, I need to pass culturally as well. Gordon and Lahelma (2002) tell us that, “constructions of adulthood emphasise independence, achieved through separation from parents, financial self-sufficiency and established heterosexual relations”. Some of this I recognise in my own situation: my own flat, independence; a regular income, financial self-sufficiency. But, wait. I should not speak to Mum every day. My emotional attachments *should* have moved on to a male partner. The first thing to remember: do not reveal the daily phone calls to Mum. Sort out a male partner instead. Continuing my literature review/undercover mission of personal deception, however, I realised that it was not that simple: adulthood seems a contradictory place to be. Furthermore, the more interdisciplinary my reading became, the more I saw that although ‘adulthood’ may not be referred to, it is more-often-than-not the unspoken assumption. When Giroux (2009) talks of the neoliberal, and Erevelles (2002) talks of the humanist subject; when Shildrick (2009) writes about the autonomous and Kelly (2006) the neoliberal self; when some within CDS reject the able and recast the temporarily able-body (McRuer, 2006); they are all speaking of what those within development/youth/psychology simply call (normative) adulthood (Burman, 2008b; Wyn & White, 1997). *Figure 1* (overleaf) illustrates the benchmarks I need to meet to pass as adult.

Figure 1 explains why I feel the need to pass as adult. To be grownup is to hold authority and respect; to be taken seriously (Burman, 2008b; Wyn & White, 1997). It is not going to be an easy task though: McRuer (2006, 9) writes that “the ideal, able-bodied identity can never, once and for all, be achieved”. Making the assumption that the ideal able-bodied identity is also adult, I agree with McRuer. For me, perhaps the most obvious issue is my gender. For a disabled young person that found themselves in my ‘trying-to-be-a-grownup’ predicament, the task is greater. Adulthood is wrapped up in ableist ideals: independence valued over interdependence; an emphasis on financial self-sufficiency; discourses of strength, power and wholeness. The final criterion is also

puzzling, whilst trying to act all grownup I have to remain ‘youthful’. Blatterer (2010, 74) explains this when he writes that “youth as a value is today replacing adulthood as a category”, meaning, “the ideal is to be adult and youthful but not adolescent” (69). The situation gets more complicated! To pass as adult I have got to hold on to some bits of youth but discard others. To figure out how to be a grownup I need to fathom what we mean when we talk about youth. With no age-bound definition, and as developmental arguments do not sit, my search must take me wider to consider cultural constructions of ‘youth’.

My detective work continues.

Adulthood Criteria	Critiques of Criteria
Autonomous Independent Sovereign	(Burman, 2008b; Davis, 2002; Erevelles, 2002; Giroux, 2009; Gordon & Lahelma, 2002; Kelly, 2006; McRuer, 2006; Shildrick, 2009; Wyn & White, 1997, 2000)
Compromising Conservative Moderate Rational Silent	(Allen, 1968; Burman, 2008b; Davis, 2002; Erevelles, 2002)
Entrepreneurial Financially self-sufficient Employed	(Giroux, 2009; Gordon & Lahelma, 2002; Kelly, 2006)
Responsible Resolved Stable Unified Whole	(Blatterer, 2010; Erevelles, 2002; Kelly, 2006)
Coherent	(Erevelles, 2002)
Cognitively Stable Knowing Knowledgeable Worldly	(Burman, 2008b; Wyn & White, 1997)
Authoritative Powerful Respected Strong	(Burman, 2008b; Wyn & White, 1997)
Masculine	(Burman, 2008b)
Fluid	(McRuer, 2006; Wyn & White, 2000)
Youthful	(Blatterer, 2010; Priestley, 2003; Wyn & White, 2000)

Figure 1: Signifiers of Adulthood

The positioning of youth in youth research

So far, youth has only been defined by what it is not: i.e. not-adult; i.e. not in possession of the signifier in *Figure 1*. This definition is unsatisfactory in many ways, but particularly as we consider ‘youthfulness’ a valued attribute of adulthood. Priestley (2003) identifies three approaches to youth research which lay outside of development psychology (though are undoubtedly influenced by it) and place youth within a social context. First, youth as a cultural category considers youth alongside cycles of production and consumption. Youth subcultural studies, predominant in the 1960s and 1970s, took this approach, considering young people as active consumers shaping markets, and constructed youth as a time for young people to test boundaries and form identities (for example, Bennett, 2008; Hall & Jefferson, 2006b; McRobbie, 2000; Willis, 1977). Second is a modernist, structural approach (France, 2007) which defines youth as a stage of life associated with particular social processes; a time prior to working life. This approach arose as industrialisation led to increased institutionalisation and was arguably more appropriate in the immediate post-war period when there were clearer coming-of-age signifiers, such as marriage, more distinct boundaries between education and work, and increased likelihoods of remaining in a job for life (Blatterer, 2010; Priestley, 2003; Wyn & White, 1997). Analysing today’s youth from this perspective has led to theorists attempting to map extended and complex transition periods (Berk, 2010; Blatterer, 2010).

Both the above examples emphasise youth as a transitory period. Transition itself has multiple meanings, referring to: a) a cultural transition, where young people leave behind the cultural positioning of child/young person by meeting the discursive signifiers of adult; b) a legal transition, where young people gain adult ‘rights and responsibilities’, such as being granted suffrage and being legally held responsible for law breaking; and, c), particularly relevant to disabled young people, a transition from children’s to adults’ services (Morris, 1999). Whatever the meaning, adulthood is the full stop at the end of youth. The third approach Priestley (2003) highlights, however, considers youth differently: relating ‘youthfulness’ with ‘the body beautiful’. Again, youth and time are inextricably linked. However, whereas with the first two approaches the emphasis is on *reaching* adulthood, a culture striving for ‘eternal youth’ conceptualises youth as a valued attribute *of* adulthood. Although when discussed *explicitly* youth is about

transience, when discursively, perhaps *implicitly* used, youth is about the desire to pause time (the focus of *Chapter Three*).

The meaning of youth is more complicated than an age-bound category: it has been abstracted from the lived-realities of young people's lives (Bennett, 2008). Messages from the media deliver similarly inharmonious messages: young people are either risky and rebellious or passive and unproductive. Either way, we want to get them to adulthood, and fast. At the same time, we are reminded whatever our age of the expectation to remain 'youthful' (Featherstone, 1982). Although I consider these contradictory and overlapping categories, I refer to these depictions as Youth as Active, Youth as Passive and Youth for Sale, categories I refer back to throughout my thesis. From my critical reading of the literature, certain disciplines and research approaches tend to trend towards a particular depiction of young people. Considering youth as a cultural category, for example, youth subcultural studies conceptualises young people as actively striving for adult identities: they are active youth, i.e. active 'becoming-adults'. Disciplines considering youth within institutional processes, however, construct young people passively moving from one service to another, pawns in a production process carving suitable adult citizens (Kelly, 2006): they are passive youth, i.e. passive adults-to-be. Research around the youth-thing of the beauty industry predominantly takes a feminist standpoint, criticising the pressure put on women to retain youthful looks, but rarely engaging with the complexity of meanings we attribute to youth: youth is simply the (abstracted) product to be critiqued, i.e. youth is for sale. Over the remainder of *Chapter One* I explore each construction in turn, whilst considering popular media messages we are delivered about 'youth'. As I argue throughout my thesis, disability must be present in theorisations of youth. CDS lenses therefore help me to critique each depiction. *Figure 2* (p. 48) offers a visual representation of this framework.

Youth as Active, Youth for Sale, Youth as Passive

Youth as Active

Although Youth as Active and Youth as Passive both begin from the assumption that young people are incomplete adults, I distinguish between young people as passive adults-to-be and active becoming-adults. Conceptualising young people as becoming-adults assumes that young people are actively a) carving out an adult identity and b) striving for independence. Government policy is surrounded with rhetoric of consulting

with young people (Department of Children School and Families, 2007a), encouraging young people to actively engage with services and politics. Youth workers are encouraged to act within these policies (Wood, 2010). However, it is only acceptable for young people to be active if they are active in the right 'adult' way (Wood, 2010). Consider British student anti-cuts demonstrations in 2010. Here we saw young people taking to the streets and occupying university, college and school campuses to oppose cuts to education, the retraction of *Educational Maintenance Allowance* (a weekly grant of £10-£30 that supported young people to stay in further education) and massive increases in tuition fees. Rather than celebrate young people's political engagement, media attention soon rebranded demonstrations as 'riots' (McSmith, Garner, Wright, & Gonsalves, 2010). Furthermore, the individualistic media response to UK 'riots' in August 2011 deemed young people criminals, rather than considering a group feeling frustrated and let down by current political systems (Brand, 2011). Although government rhetoric wants to consult with young people, these consultations are searching for particular answers; we do not want young people to be *too* active. Although we may consider youth as active, we do not consider youth as rational, as, to be rational, one must be adult. Therefore, active youth without adult mediation leads to disruptive, reckless and dangerous young people (Giroux, 2009). In terms of politics, young people are construed as naively idealist, and with this the connotation of stupidity, and self-indulgence.

Disabled young people are rarely positioned as active youth (Slater, 2012b). However, if we are to look discursively at associations made with disability, parallels can be drawn. Davis (2002) talks about disease, writing that whilst the normative body is silent and moderate, an ill body is equated with excess and excitement, either hypo or hyper, and leads to connotations of noise, attention, irritation and stimulation. Similarly, Shildrick (2009) highlights that the 'able-body' is unspoken, almost redundant and only taken into consideration if it is in some way 'different' to the pseudo-norm. Those considered 'differently embodied' are judged as morally-deficient (Garland-Thomson, 2002). Similar assumptions are made of young people: 'hoodie' acting as a synonym for young person (BBC News, 2005). Disability is further associated with incoherence (Erevelles, 2002), again, an association that can be linked with both the passive and active youth: 'text talk', 'new-fangled' language and teenage 'grunting'. Youth and disability both linked with deviation. Furthermore, in the same way that the non-disabled body is implicit, something McRuer (2006) calls compulsory able-bodiedness, adulthood is an

area that there has been little attempt to theorise (Blatterer, 2010). Although we link youth with becoming-adult, what we mean by adult is an implicit belief, crying out for interrogation. Campbell (2009) calls to theorise the ‘able-body’; theorising the ‘adult social body’ is key to theorising youth. I consider neoliberal conceptions of adulthood in *Chapter Two* and young disabled people’s thoughts around youth as becoming-adult in *Chapter Seven*.

Youth subcultural studies has been accredited with carving positive pictures of active youth (Hodkinson, 2008). The 1950s and 60s saw some young people in the possession of disposable incomes, resulting in the development of ‘youth markets’. Youth subcultural studies looked at youth cultures developing from these markets alongside cycles of production and consumption: positioning youth as active, discerning consumers, re-appropriating market commodities. Ethnographic research concerned the lives of young people engaged in ‘deviant’ subcultural activity, often based around particular tastes in style and music – mods, rockers, punks, teddy boys, and so on. However, rather than conceptualise deviance as negative, youth subcultural theorists saw deviant behaviour as metaphorical of wider social change: simultaneously acting within, reflecting and challenging political landscapes (Hall & Jefferson, 2006a). By the 1980s, however, the discipline was criticised for only engaging with public accounts of male youth – ignoring the often more private lives of young women. As McRobbie (1980, 41) puts it, “few writers seemed interested in what happened when a mod went home after a weekend on speed. Only what happened on the streets mattered”. Feminist scholars have addressed this, and other intersections of race and sexuality have also been considered (Rattansi & Phoenix, 2005). Disability, however, is still rarely mentioned (Butler, 1998).

Priestley (2003) is not alone in highlighting the barriers for disabled youth to youth cultures (see also, Hughes, Russell, & Paterson, 2005). I do not dismiss this, however, I am wary of relegating disabled young people to the realms of passive youth; a lack of engagement between youth cultural studies and CDS should not assume a lack of participation of disabled young people in youth cultures. Research question two asks, how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient? *Chapter Six* approaches this by synthesising youth subcultural and CDS arguments.

Youth for Sale

Considering youth alongside production and consumption, youth subcultural studies overlaps *Youth as Active* and *Youth for Sale*. I employ the term youth subcultural studies for the sake of clarity. However, recent postmodern discussions have deemed the term ‘youth culture’ empirically inaccurate – unrepresentative of cultures that are bought into cross-generationally (Bennett, 2008; Sweetman, 2001). Bennett (2008) writes that “the ‘reality’ of youth is being constructed for us, and for young people themselves, by empowered ‘outsiders’ – journalists and other social observers with access to the ‘official’ and ‘authenticating’ channels of the media who use this power to express a particular point of view” (Bennett, 2008, 30). He highlights that signifiers of youth are no longer age-bound, but available to be bought into *despite* age; ‘youth culture’ as a way of feeling, rather than a way of being. Yet these are cultural experiences that may prove inaccessible to disabled youth (Priestley, 2003). Hughes et al. (2005), warn us that although “youth and its signifiers will sell, disability will not!” Youth is entwined with a discourse of ideal bodies; equated with beauty, health, strength, energy and sexualisation (Heiss, 2011). Disability, traditionally paired with asexuality (Garland-Thomson, 2002), does not immediately sit with these ‘sexy signifiers’ of youth.

Beginning with the assumption that the body is discursively and culturally ascribed with meaning, feminist scholars have critiqued notions of the ideal body, highlighting that the ideal body is always young (Heiss, 2011). This does not mean, however, that the young body is always ideal. The body of a young disabled person, for example, may not meet up to the societal expectations of ideal beauty. A feminist-disability perspective, I argue in *Chapter Three*, adds depth to an exploration of bodily perfection. The ableism surrounding adulthood and youth is highlighted; although there is an infantilisation of disabled people, the commodification of youth ensures those differently embodied remain outside the realm of ‘the beautiful’. Such commodification, however, arguably ousts all empirically young people. It is only acceptable to hold these sexy signifiers of youth, if one is ‘adult enough’. The sexualisation of youth spans passive, active and commodified youth. Young people are on the one hand passively in need of protection from adult fetishisation (Criminal Records Bureau vetting procedures, a police check required in the UK to work with children and other groups deemed ‘vulnerable’, illustrate this). On the other, they are depicted as actively and problematically highly sexualised and sexually driven, whilst being simultaneously promoted and commodified as sexually desirable. Shildrick (2009, 60) similarly highlights the complexity of discourses around

sexuality and disability: disabled people both construed as asexual yet fetishised. These arguments are extended in *Chapters Three* and *Eight*.

Davis (2002) takes a cultural CDS stance to sum up strives for eternal youth in his discussion of care of the body. Care of the body involves the consumption of vast numbers of products, without which, we are incomplete. He argues that buying into the cosmetic industry has become a requirement of citizenship. Giroux (2009) makes a similar argument specifically in relation to the commodification of youth. Referring to the biopolitics of commodification (populations being regulated through processes of commodification), he argues that at best young people are useful consumers, at worst, they are a threat. The power of consumption strengthens the discourse of individualism; it is not that you merely want something, it is that you need it, as without it, without being a consumer, you cannot be a citizen. Failed consumers become part of the disposable population.

Youth as Passive

Passive youth fit into this bracket of failed consumer. Youth as Passive underpins most government research concerning young people, especially disabled young people. It considers young people as adults-to-be, taking a structural approach to conceptualising youth. Young people are pawns, passed from one service to another (France, 2007; Priestley, 2003). Wyn and White (1997) highlight that such an approach considers young people in a pre-social state, and that given the right conditions they can be shaped to become 'suitable adult-citizens'. On one level, this leaves society with responsibility towards a supposedly powerless and vulnerable group. However, it also leads to the less paternalistic and more demonising depiction of lazy, ignorant and apathetic young people. Neoliberalism, associated with the politics of the right, sees a step away from state-controlled systems to one based upon market values, resulting in privatisation such as that we see in Britain today. The 'teenage slob' presents a problem to neoliberal ideals, as *not* acting poses as a challenge to the competitive, entrepreneurial subject valued by the UK's Conservative/Liberal Democrat coalition government (and the preceding New Labour). Conversely, the same labels of stupidity and self-indulgence are equally applied to passive youth. A passive generation, however, also means a malleable generation, and the negative portrayal of apathy legitimises the 'need' for adult, often

professional intervention to carve young people into active independent citizens that are valued in a neoliberal society (Kelly, 2006).

Kelly (2006) argues that those least likely to meet the neoliberal ideal are labelled ‘youth-at-risk’. For some ‘at-risk’ groups (here I would put working class youth and black boys, for example), the perceived ‘risk’ is activity (again, see UK media coverage of the August 2011 ‘riots’). For disabled youth, however, the perceived ‘risk’ is passivity. As Priestley (2003) highlights, leisure opportunities for disabled youth (such as youth services offering ‘life skills’ courses) often focus on preparing for a ‘meaningful’ life without work. In criticising service provision, however, it is important to tread carefully: at the time of writing welfare services are facing massive cuts, which will undoubtedly impact on the lives of young and disabled people and I am wary of not adding to the ammunition of the UK coalition government. There is no need to further legitimise government cuts to services offered to young and disabled people. The depiction of disabled people as passive, dependent and a drain on resources proved particularly dangerous at the time of eugenics movements, and the coalition government are today painting a similar depiction to justify their destruction of the welfare state (Garthwaite, 2011) – addressed in *Chapter Two*.

Although speaking in an American context, Giroux’s (2009) engagement with the biopolitics of commodification resonates scarily closely with Britain’s welfare-cutting political situation. Giroux (2009, 31) cites Bauman when he writes, “in the society of consumers no one can become a subject without first turning into a commodity”, and, a commodity must be flexible enough to be remarketed in order to avoid being disposed of. If youth has been commodified, idealised and made into a sellable thing, it is also disposable. A market commodity has to be flexible (we see this in our signifiers of adulthood) and able to remarket itself, in order to remain sellable. Placed in the realms of passive youth, disabled people fall into the disposable population of ‘failed consumers’ that Giroux discusses. The construction of disabled people as passive, is used to legitimise welfare cuts (Garthwaite, 2011) which ironically carry with them an increasingly penetrating welfare gaze. Furthermore, considering disabled youth as passive, furthers the arguably well-meaning paternalistic, ‘it’s-for-their-own-good’ attitudes that restrict and oppress disabled people, particularly those with the label of ‘intellectual impairment’. I extend these arguments in *Chapter Two*; before going on to

challenge the positioning of disabled youth as passive through time spent with young disabled participants over *Section Two*¹.

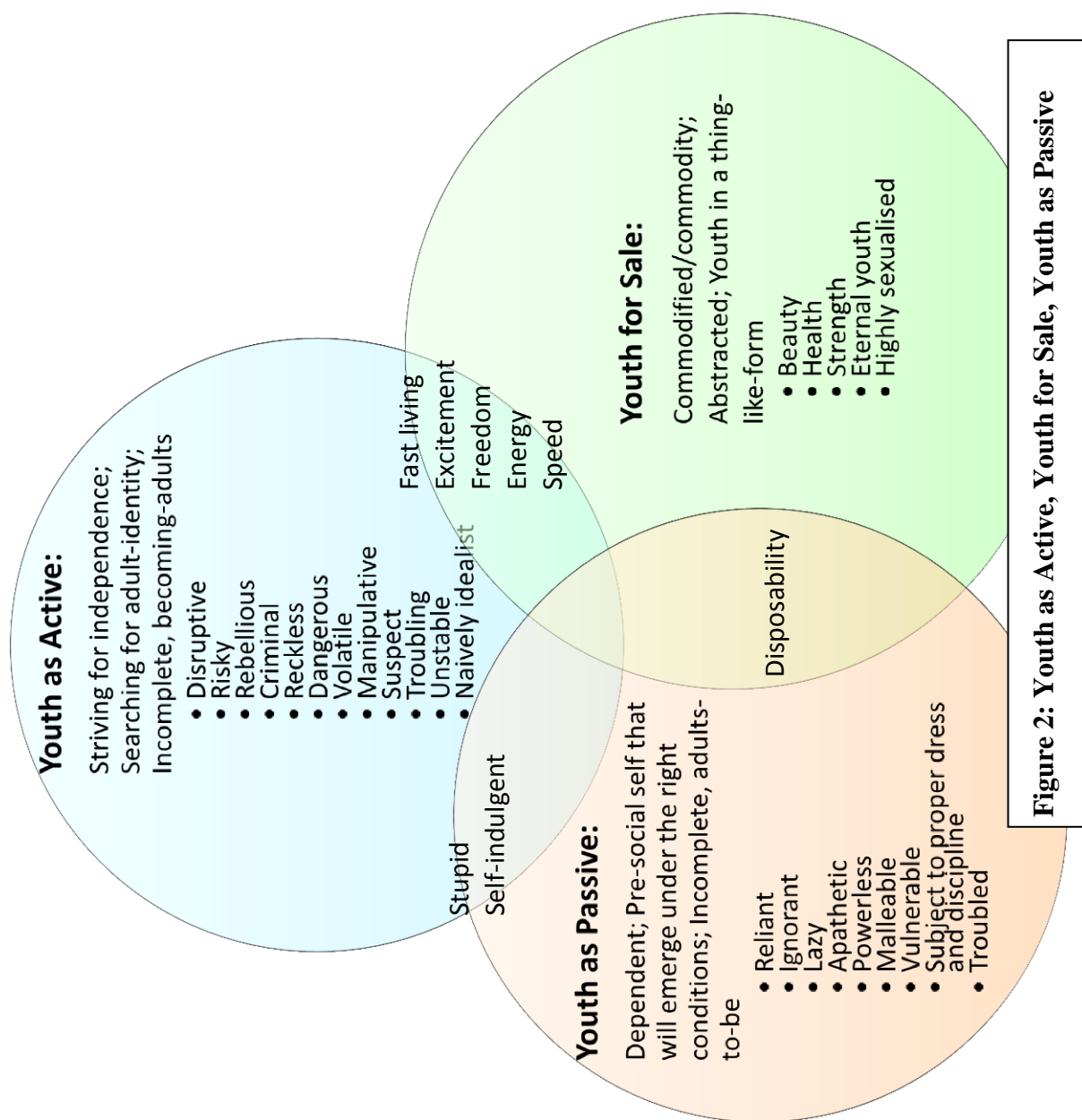


Figure 2: Youth as Active, Youth for Sale, Youth as Passive

¹ Although the notions of Youth as Active, Youth as Passive and Youth for Sale do not correlate directly to particular chapters of analysis in Section Two, all arise as concepts in analysis.

Discussion

This chapter has begun to unpick messy and contradictory discourses surrounding youth and adulthood. The quest I set out at the beginning of the chapter was to convince you all of my grownup status. We have seen how normative assumptions inherent to developmental discourse precariously position young and disabled people, thus justifying further exploration of research question one: what dangers do young disabled people face if normative discourse remains unquestioned? Investigating adulthood leads me to think maybe I do not want to pass as adult after all. So, I am ‘coming-out’. It seems more fun to be excitable, attention-seeking and irritating, than silent, moderate and conservative. Moreover, as I develop throughout my thesis, such a declaration is important for a solidarity politics of youth. Butler (1993b) distinguishes between being virtually queer, “which would be experienced by anyone who failed to perform heterosexuality without contradiction and incoherence (i.e., everyone)” (McRuer, 2006, 30), and critically queer, which would mean “working to the weakness in the norm”, using the inevitable failure to meet up to this ‘ideal’ as a way of mobilising. McRuer (2006, 30) draws on this to make the distinction between being virtually disabled and, what he terms, “severely disabled”; a distinction I expand upon in *Chapter Five*. As we have established the impossibility of meeting up to the adult-ideal, from this point onwards I take up a critically young position; a cultural position I develop from *Chapter Four* onwards.

This chapter alerts us to the importance of critically questioning discourses of youth, adulthood and disability. The particular angle I am taking is to consider the situation of disabled young people, and using disability as a conceptual lens to think-through youth (and adulthood). I began to explain my reasons for taking this stance in the introductory chapter, and I extrapolate them as I go on through *Section One*. *Chapter Two* focuses on the construct of Youth as Passive within a consuming society. I argue that as a group positioned as passive (Hughes, 2001), current individualistic neoliberal drives in the UK prove particularly harmful to disabled people. Here I address research question one: what dangers do young disabled people face if normative discourse remains unquestioned? I also highlight the need for research question two, how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient? *Chapter Three* concentrates on Youth for Sale to further justify my use of disability. I argue the importance of adding disability to a feminist analysis of the commodification of youth. *Chapter Four* outlines why I believe that, thought together,

disability and youth can help us thinking-otherwise about one-another; a sentiment at the crux of research questions three and four: what can disability and the lived-experiences of young disabled people teach us about youth? What can youth and the lived-experiences of young disabled people teach us about disability? I argue that disability can help free us all from the need to play grownup

However, as this chapter makes clear, considering the lived-realities of other young people deemed outside of normative ideals is also important. Discussions around youth, disability and adulthood, should not happen in isolation. We need conversation between different researchers and disciplines. I plunder from various theories and disciplines throughout my thesis (Hughes, et al., 2012). If the UK ‘riots’ of summer 2011 have taught us anything, it is that we need to start listening to young people. This should and must include disabled youth.

Chapter 2

Disability and Youth as Passive in British Political Climates

Introduction

In May 2010, amidst the ‘global financial crisis’, a Conservative/Liberal Democrat coalition government succeeded a 12-year reign of New Labour. Following the work of Thatcher, New Labour imposed a series of backhanded privatisations. Schools were re-branded academies and affiliated with big business and agendas such as *Every Child Matters* conceptualised the child as entrepreneurial (Goodley & Runswick-Cole, 2011b). However, since the arrival of the coalition government the train to neoliberalism has accelerated (Roulstone & Prideaux, 2011): Britain’s public services under threat and local councils are forced to make massive cutbacks. In this chapter I address research question one, asking what dangers young disabled people face if normative discourse remains unquestioned in current political climates. I argue that the individualistic neoliberal doctrine makes embodying ableist, normative adulthood (*Figure 1, p.40*) a means of survival. In order to justify welfare cuts those not embodying normative adulthood are construed as passive and burdensome. Young disabled people are relegated to the realms of Youth as Passive. I argue in this chapter that the positioning of disabled youth as passive is dangerous. Thus, I highlight the importance of research question two: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient?

In counter-distinction to *Chapter One* where I used disability as a conceptual lens to consider discourses of youth, in this chapter I start with the positioning of disabled youth; beginning with a brief review of literature focusing on disabled youth. Much literature considers disabled young people within service and institutional settings (considering the transition between school and work, for example) (Priestley, 2003). Although I maintain the importance of service-based research, I argue the importance, as disability researchers, of broadening our methodological thinking around disabled youth in order to a) remove disabled youth from rhetoric of passivity; b) consider their lives outside of service-provision; and c) question ableism of adulthood discourse. To justify these

arguments, I turn to consider how changing policy legislation impacts on disabled people; an analysis which leads me to consider the representation of young and disabled people under the cuts. Introducing an imagined conversation between myself and Conservative welfare minister, Lord Freud, I use Foucault's notion of gaze to assess the consequences of a welfare gaze. Drawing on Giroux (2009) I will argue that under the rule of the coalition government the dangerous consequence for young, disabled, and other people not meeting normative signifiers of adulthood, is one of disposability. I suggest that as researchers, there may be times we need to argue disabled youth into normative adulthood discourse, however, it is equally important to question valued attributes of adulthood (arguments furthered in *Chapter Seven*).

Researching disabled youth and transition

Today's young people are likely to stay longer in education, live with parents and delay pre-industrial signifiers of adulthood such as marriage and having children, than previous generations (France, 2007). Research considering young people's lives alongside structures traditionally thought to aid their transitions to adulthood has therefore declined (France, 2007). That is unless the research concerns disabled youth (Priestley, 2003). One could legitimately argue that disabled youth are more likely to be accessing services than their non-disabled peers and research is therefore necessary to review and revise these services. As I expand upon below, welfare services current face massive cuts, which are impacting upon the lives of young and disabled people. Research is further needed to make clear the impact of removing such services. Murray (2002, 3), for example, voices two disabled young people's comments that a 'segregated' leisure scheme in their area "saved their lives" as it allowed them to make friends with other disabled young people whilst realising the isolation they were feeling in mainstream school was also being experienced by their peers.

Transition-based research focusing on service-provision for disabled youth is not homogeneous. It is carried out within national and regional level government departments. *Aiming High for Disabled Children (AHDC)* (Department of Children School and Families & Department of Health, 2007) and *The Children's Plan* (Department of Children School and Families, 2007b), for example, were both New Labour policy drivers set out in a response to dissatisfaction with services for disabled children (Goodley & Runswick-Cole, 2011b). Service-driven research also comes from charitable trusts and campaigning organisations (Beresford, 2004; Every Disabled Child

Matters, 2011b; Hendey & Pascall, 2002; Murray, 2002). In addition, research not directly affiliated with particular services such as that from within CDS aims to influence services (see, for example, Campbell, Goodley, & Runswick-Cole, 2011; Rabiee, Priestley, & Knowles, 2001). There is crossover between research: disability researcher, Morris (1999, 2002), for example, was funded by the charitable trust, *Joseph Rowntree Foundation*, to write reports on disabled young people's transitions to adulthood. As universities are required to assess the impact of their research, there are pragmatic reasons for the large amount of research in this area: if research can be shown to directly influence government policy, there is more chance of future funding.

Research question two asks how disability researchers can share the stories of young disabled people in order to reposition them as active and politically resilient. To address this question I am interested in what message CDS literature gives us about disabled youth. Much of what we are offered is a message of 'sameness': we are told throughout this body of work that young disabled people have the same aspirations as their non-disabled peers, but material and attitudinal barriers make it harder for them to meet these aspirations. One way of removing such barriers is through service provision which young people themselves should be in control of (Hendey & Pascall, 2002; Morris, 1999, 2002; Rabiee, et al., 2001). Morris (2002, 10) notes that service providers should "recognise that transition is a process, rather than a series of assessments and reviews; and that disabled young people's transition to adulthood may well take longer – because of the barriers they face – than that of their non-disabled peers". Hendry and Pascall (2002, 732) argue that disabled young people aspire to "achieve adulthood through employment, to gain resources for independent living in their own choice of housing, wider social networks, escape from poverty, and a sense of contributing to society." And Morris (2002, 7) is not alone when she highlights that "sex and sexuality figure as important issues in the transition to adulthood for non-disabled young people but adults do not always recognise that disabled young people will have the same sexual feelings as others of their age. This can result in a lack of information and in inappropriate advice, creating confusion for young people, their parents and carers". Literature concerning both disabled and non-disabled youth tells us "constructions of adulthood emphasise independence, achieved through separation from parents, financial self-sufficiency and establishment of heterosexual relations" (Gordon & Lahelma, 2002, 2).

That there is a need to assert that the aspirations of disabled young people are similar to those of their non-disabled peers is telling. It speaks of the general assumption that to be disabled is to be different – should we be surprised that disabled and non-disabled young people have similar hopes and dreams? Non-disabled and disabled young people are being delivered the same message that to be successful is to meet up to normative adulthood expectation. Arguably, this message is delivered to disabled young people (and others that it is worried are less likely to meet convention) louder and stronger (Kelly, 2006). Scholars have noted that although young people’s priorities tend to be ‘here-and-now’ experiences of fun and friendships, even *leisure* services for disabled youth focus on “learning life skills, increasing independence and/or self-esteem” (Murray, 2002, 1) and preparing for a “meaningful life without work” (Priestley, 2003, 91). Add to this an ‘overcoming’ or ‘supercrip’ narrative of disability (Barnes, 1992; Deal, 2003), and we understand that disabled young people may feel the pressure to meet up to adulthood expectation more than their non-disabled peers in order to ‘prove themselves’.

My worries with current approaches to research are therefore multiple. Firstly, I worry that researching around disabled youth only in relation to service provision does not demonstrate their lives outside services (Priestley, 2003). Secondly, without denying young disabled people’s right to aspire to adulthood normativity, I feel we must be alert to tokenism within research (Fullagar & Oowler, 1998). Considering the above, it is not surprising that when asked, often from within a service delivering this very message, that disabled young people answer that they aspire to normative signifiers of adulthood. As disability and youth researchers we need to develop methodologies which give young dis/abled people the opportunity to think outside a box of normativity (Goltz, 2009). I address these kinds of methodological questions in relation to my own fieldwork in *Chapter Five*. Finally, like Campbell (2009), I believe stepping away from only theorising disability, to consider ‘difference’ more widely can help us think less oppressively around disability. For my project, this means asking how implicit discourses of youth and adulthood work alongside the disabled identities of young disabled people to impact upon what they can do and be; the heart of research questions three and four: what can disability and the lived-experiences of young disabled people teach us about youth? And what can youth and the lived-experiences of young disabled people teach us about disability? For me, much research around disabled youth fails to address the ableism of discourses of youth and adulthood (Davis, 2002).

As further outlined over *Section Two*, although I believe arguing disabled young people's 'sameness' to their non-disabled peers is strategically important, I also believe my job as a CDS youth and disability researcher is wider than this. Currently, those actively challenging and resisting structures imposed upon their lives in ways considered outside of normative democratic processes, are demonized; their political acts deemed as irrational and irresponsible (Slater, 2012b). For disabled young people, anger and frustration is quickly individualised as 'challenging behaviour'. Asking wider questions about difference helps us to join hands with those not wanting/able to conform to adulthood normativity. I turn to justify my above arguments by considering the place of young and disabled people under the coalition government.

Young and disabled people under the coalition government

One could argue that today more than ever research needs to consider the material oppression in young disabled people's lives. I outline here just a few examples of how welfare reforms are hitting young and disabled people:

1. It has been calculated that "disabled people and their carers have seen their income collectively cut by £500m in the past two years" (Butler, 2012b). A figure that is only going to increase as welfare cuts deepen.
2. "Six per cent of doctors have experienced a patient who has attempted - or committed - suicide as a result of "undergoing, or fear of undergoing" the Government's fitness to work test" (Clark, 2012).
3. At the beginning of the 2011-2012 financial year children's services faced cuts of £819 million and disability services £4.4 billion. With school's funding ring-fenced, effects of children's service cuts were arguably felt most greatly by young people (Butler, 2011).
4. Since the change of government, young people have faced the end of *Educational Maintenance Allowance*, rising tuition fees in higher education, mass unemployment and the threat of loss of housing benefit for under 25s.
5. The shift from Disability Living Allowance (DLA) to Personal Independence Payments (PIP) means "almost a third of working age disabled people will no longer qualify for the enhanced mobility component of DLA that currently enables them to lease a car under the Motability charity scheme" (Butler, 2012a).

For all young people, but especially disabled youth, those taunting signifiers of adulthood independence and financial self-sufficiency are ever more illusionary under The Coalition.

Massive figures grab headlines, sound, and *are* frightening, but when numbers are so large what they mean is hard to fathom. What is clear is that it is the poorest suffering most. At the time of the budget 2012, a report from *The Institute for Fiscal Studies* warned that those hardest hit by The Coalition's austerity programme were families with children; those least well off, losing out most of all (Elliott, 2012). Families with disabled children, it has been consistently shown, are proportionally more likely to live in poverty than those without (Every Disabled Child Matters, 2007, 2011a; Sharma, 2002). Recent research highlighted that one in seven working families with disabled children and one in four without work are missing meals. One in six working and one in three non-working families are left unable to heat their homes (Every Disabled Child Matters, 2012). Cuts such as these, along with a 50% cut in disabled children's benefits and less available finance leaving short breaks vulnerable to reductions, means disabled children, young people and their families are being hit hard (Every Disabled Child Matters, 2011a).

As the stories become more personal, the situation becomes easier to comprehend. It was announced in April 2011 that housing benefit for working aged people would be linked to property size. *BBC News* (2011) told the story of wheelchair-user Sandra Ruddicks. Since Sandra's family have now grown-up and moved out, she lives alone in the specially adapted two-bed social housing property which she brought her children up in. Under the reform Sandra, along with an estimated 108,000 other disabled people could be forced to leave their homes, as they are considered to be taking up unnecessary space. At the end of the broadcast, Lord Freud², Minister for Welfare Reform, legitimised the move, arguing the importance of people living in houses that are the "right size for them", in order for it to be fair on the "ordinary person who does not depend on benefits". Nobody asked Lord Freud how many bedrooms his house has, or suggested he

² As Lord Freud will become a bigger player in this chapter, it seems only fair to fill you in with more details. Former advisor to the Labour Party, Freud drew up plans to revise the welfare system, publishing the 2008 *Welfare to Work* Green Paper which called for measures to get more disabled people and lone parents into work. Although many Labour backbenchers opposed Freud's proposals, it was music to the ears of Tory ministers. In February 2009 Freud controversially joined the Conservative Party as Shadow Minister for Welfare and was given life peerage in the House of Lords. As Minister for Welfare, Freud is the architect of *The Welfare Reform Act 2012*, the implications of which are critiqued in this chapter. Conversely, he is the grandson of Sigmund Freud.

should downsize, to make it fair for the “ordinary person”. A friend of mine accessing DLA made the effects of coalition policies all too clear when he said, “I feel like they’ll take away my money if there’s any chance I’m having any fun, or even leaving my flat for that matter”.

Above are just a few examples of how the cuts may affect poor people, young people and disabled people. There are, of course, many more intersections of identities to consider. Women more likely to be employed in low-paying public sector jobs more greatly affected than men (Veale, 2011). The end of specialised services aimed at LGBT and BME communities (Bawden et al., 2011). The slashing of funding to law firms offering specialist advice to asylum seekers (BBC News, 2010). All exemplify the disproportionate and potentially devastating impacts. Those facing unemployment/the loss of vital service provision are further subject to an entourage demonising rhetoric. The claim: that any increased hardship is a result of individual laziness and failure (Garthwaite, 2011; Hughes, 2001). Disabled people have shown their anger towards public service cuts by demonstrating under the slogan *The Hardest Hit*. In concurrence with the choice of slogan, my analysis above hints that disabled people will be one of the hardest hit groups. Having briefly outlined the very real, material oppression in the lives of those affected by the cuts I turn to consider the resultant media positioning of disabled people (young and old). An (unreal) discursive positioning that I will show has very real consequences. I will feed this analysis back into my work around youth in the final section of this chapter.

The representation of disability in current political climates

Chapter One considered issues of representation. Although I found definitions of ‘youth’ were inconsistent, even within the limited scope of UK policy, discourses of youth reflect, add to, and act within social, cultural and political (including popular media) representations. They therefore form our perceptions, constructions and expectations of young people. Drawing on Dyer, Titchkosky (2000) reminds us that representations are not a ‘true’ reflection of ‘reality’. Representations cannot reflect the extensity and complexity of ‘reality’. One representation cannot represent a heterogeneous group of people. Representation is dependent on interpretation. A representation cannot be isolated and only works in relation to other representations. Yet, representations do have very real consequences for very real people. The headline, ‘*Disabled people face abuse*

and threats of violence after fraud crackdown' (Boffey, 2011), brings the 'unreal' of representation crashing into 'reality'. A survey commissioned by disability charity *Scope* reports that disabled people have experienced increased hostility, discrimination and physical attacks (the majority, shockingly, on at least a weekly basis) as ministers have portrayed "all people with disabilities as scroungers as they seek to cut the number of people on disability benefits" (Boffey, 2011). On top of losing vital services, disabled people face real consequences of unreal representations of disabled people. Disability and youth researchers must consider representations of dis/abled youth, as behind such representations there is an agenda:

"... consequences [of representations] go beyond the people being represented, since there are consequences for those who make the representations as well. The most authoritative representations of disabled persons arise from medical and/or therapeutic disciplines, and the social sciences. Anyone who is to be regarded as "in the know" about disability must show that they know what is the problem and the more details they possess of the problem, the better. This is the "official textbook" of disability represented in our culture"

(Titchkosky, 2000)

Representations of others, not only *impact* upon, but *define* representations of ourselves and the selves of people deemed Other (Goodley, 2011). Representations of a deficient Other concrete the vision of the whole and stable self. Disability stands as one such Other to convince us of the (untrue) 'reality' of the able-bodied self (Goodley, 2011; Hughes, 2001; Shildrick, 2009). In *Chapter Four* I argue that portrayals of youth function similarly.

What is going on when ministers portray disabled people as scroungers (Boffey, 2011)? When Lord Freud juxtaposes the benefit claimant with "ordinary people" (BBC News, 2011)? The message is not hard to decipher. We are in a financial mess, that, we know. But, do not worry, ordinary people, for the ministers and Lord Freud have found the problem! And that problem is the Other: the disabled, the benefit claimant. It is not *us* that are to blame - meaning me, you, the ministers and Lord Freud... the presumption is that you (the watcher/reader/listener) and are one of *us*, not one of *them* (Titchkosky, 2000). No, it is not *us* that have created this problem; me and you, *we* are the *ordinary*, the *normal* people – *we* are in this together. It is *them* you should be blaming: the disabled, the benefit claimant, the scroungers. It is *them* that got *us* into this mess (Sloan, 2010). But, of course, culture's '*ordinary man*' is law's '*reasonable man*' (Campbell, 2009). If, therefore, I was to tell Lord Freud that I am one of *them* (I *am* the disabled, the

benefit claimant – “Lord Freud, I *am* your scrounger”), he would respond (with an awkward chuckle and a pat on the head), that he knows some people are *really* disabled, *really* in need, *really* deserving: “I’m a reasonable man, Miss Slater” – (at which point I remind him, for the third time, I prefer Ms Slater) – “but, Miss Slater, there are some people out there taking advantage of us reasonable, ordinary people.”

The above tale is not true, but an imagination. I have never met Lord Freud, nor am I disabled, nor do I claim benefits. That conversation never happened. I would argue though that my imagined, untrue conversation is closer to a ‘truth’ than the very untrue representation of disabled people as scroungers, yet we have seen that the depiction of disabled people as a drain on society is an untruth with very real consequences. I am reminded of Foucault’s (1973) notion of gaze. The nineteenth century, Foucault (1977) argued, saw a shift from sovereign power, demonstrated grandly yet sporadically through public torture and execution, to an enduring and less visible form of disciplinary power (Rouse, 2007). Rather than acting top-down, disciplinary power permeates day-to-day living, acting through and being performed by individuals, whom Foucault terms ‘vehicles of power’. Disciplinary power makes knowledge and power inseparable, resulting in discourses of power-knowledge. According to Foucault, as ‘vehicles of power’ no individual is outside of the system of power-knowledge, rather systems (which he describes as carceral and Panoptic) create self-surveying, confessing and docile bodies (technologies of the self) which gaze upon the bodies of others whilst simultaneously surveying themselves.

Discourses of power-knowledge, left unchallenged, become false ‘truths’ (Stein, 2010), or, as Titchkosky (2000) puts it, ‘official textbooks’. ‘Official textbooks’ of disability tell us that disabled bodies are abnormal, and should be regarded less highly than ‘normal’, ‘able bodies’ (Butler, 1993a; Hughes, 2005). By casting disabled people as Other, ‘official textbooks’ of disability work through a disciplining ‘gazing’ culture to ensure we keep a *particularly* careful eye on problematic disabled bodies (Biggs & Powell, 2001; Hughes, 2005; Shildrick, 1997). Foucault tells us that this gaze does not just come from doctors and others within the medical profession (Shildrick, 1997). We are all expected to gaze upon ‘abnormal’ bodies. “Physical difference [...] makes the bodies of disabled people public property” (Barton, 1993, 243), something Lord Freud is drawing on in the imagining reiterated above.

Hughes (2001) points to dependency as another untrue ‘truth’ of the textbook of disability. The dependency/disability story goes as follows. Disability is a deficiency, an abnormality, a biological fact. This deficiency is a tragedy that leaves disabled people dependent and in need of care. Thus, “[t]he ‘invalid’ [the wrongly posited disabled person] is a fiscal burden but one who deserves the support and succour of the community” (Hughes, 2001, 24). Garthwaite (2011) highlights that David Cameron understands this story when he states that: “if people ‘really cannot work’, then they will be looked after” (Cameron cited in Garthwaite, 2011, 370). As we can see from our own imagined story, the textbook has taught Lord Freud well. As a reasonable man Lord Freud understands that disability is a tragedy. It is only reasonable, only humane, to be charitable towards those less fortunate than ourselves. This is a story he recounts to me: his problem, I must understand, is not with those who are *really* disabled, but those who are masquerading as disabled, those not-really disabled people, taking us ordinary, reasonable people for a ride. I get it now! “Oh”, I exclaim, “how reasonable of you, Lord Freud – now I really do see what a reasonable man you are! You just want to locate those unreasonable others!”...but then it dawns on me, “...but, Lord Freud, “how are *we*” – (yes, *we*: me and Lord Freud, we are now a *we*, an *us*, united against *them* – he has convinced me that *they*, the not-really or not-disabled-enough disabled people, are the Other, not me) – “how are *we* going to separate the two? How do *we* find out who’s *really* disabled?” Luckily for me, Lord Freud has the answer, “simply, Miss Slater, through the increasingly penetrating welfare gaze.”

Perhaps now even the imagined reality of my story is becoming less imaginable. Lord Freud is himself drawing on Foucault, and Foucault would strongly dispute Lord Freud’s conscious compliance in any process of gaze, as, part of the doctrine of ‘governmentality’ is that it renders bodies docile in the process of self-governance. Hence, power is made invisible (Giroux, 2009; Rouse, 2007). Let us continue imagining, however, long enough to ponder what is happening in my dialogue with Lord Freud. Firstly, what Lord Freud means when he talks of the ‘welfare gaze’. With the welfare gaze comes an expectation of self-governance. Those accessing welfare services are expected to assess and govern themselves through self-assessment processes. In contrast to the focus on ‘aspirations’; the encouragement to actively strive for ‘independent’ ‘adult’ lives in the service-led rhetoric we saw earlier, in order to access benefits and services disabled people must prove they are ‘disabled enough’ by filling in forms declaring what they cannot do. With less access to welfare and benefits, the form

increases in volume and length, and the expectation of self-surveillance is heightened. Question 36 of the DLA form asks: “Do you usually have difficulty or need help with your toilet needs?” (Department of Works and Pensions, 2009, 18) On answering ‘yes’ the claimant is required to go into further detail: how often do you need help? For how long? Do you struggle to concentrate and need motivating with your toilet needs? How often? For how long? Shildrick explains this process as such:

“In focusing on singular behaviour, the state-sponsored model of disability promotes individuals failing above any attention to environmental factors. The DLA pack rigidly constructs and controls the definitional parameters of what constitutes disability in such a way that those who need to place themselves within that definition are obliged to take personal responsibility in turning a critical gaze upon their own bodies... power/knowledge relies on self-surveillance”.

(Shildrick, 1997, 51)

Goodley and Runswick-Cole (2011c, 602) write of the “multi-faceted violence in the lives of disabled people”. Parents having to “explain their [disabled] children’s health, demeanour, comportment or behaviour in terms of culturally acceptable disability discourses” rather being able to “offer more enabling alternatives” that are less alien to the way they think of their children, illustrate disablism, psycho-emotional violence (Goodley & Runswick-Cole, 2011c, 609). Psycho-emotional violence “undermines the emotional well-being of disabled people and can be just as disabling as structural barriers” (Reeve, 2002, 493). The same argument applies to those required to fill in such forms about themselves: processes of self-surveillance amount to psycho-emotional violence. The reality of this psycho-emotional violence for disabled youth becomes clear in *Section Two*. Furthermore, the Scope (Boffey, 2011) report alerts us that on top of psycho-emotional violence, representations of disabled people as scroungers mean an increase in what Goodley and Runswick-Cole (2011c) term ‘real’ violence:

“Real violence is experienced physically and psychologically. [...] The real of violence is an embodied encounter: of pain inflicted by one body on another. [...] real physical encounters with violence; pain, humiliation and, we could suggest, torture.”

(Goodley & Runswick-Cole, 2011c, 606)

With the rhetorical intention to decrease the power of the welfare state in favour of the markets, disabled people not only face increased material inequality, but an ever-more penetrating welfare-gaze, and dangerous representations of disabled people which have

violent consequences (Goodley & Runswick-Cole, 2011c). I now consider how this relates to my discussion of Youth as Passive.

Theorising activity and passivity within consumerist discourse

Priestley (2003) argues the ease of positioning Youth as Passive when taking a structural approach to research, even when research or services aim to empower. As Goodley warns us:

"When professionals seek to 'empower' people with learning difficulties, there is a danger of reinforcing the victim status of people with learning difficulties"

(Goodley, 2005, 334)

Passive young people are either lazy, apathetic and a drain on society, or victims, in need of charity, care and protection: constructs we saw in the previous section in relation to disability. Although (under the charity model of disability) we feel obliged to care for the latter group, we are encouraged, through the welfare gaze, to 'watch out' for the former. With cuts to welfare provision, we are expected watch out for fakes within the system. Ironically, although with the increased welfare gaze comes rhetoric of ending dependency, according to Foucault gaze encourages dependency and passivity by rendering bodies docile (Hughes, 2001). He terms this relationship between the body and power as bio-power:

"For Foucault, the human subject in modernity is constituted by disciplinary techniques of bio-power which structure, produce and optimise the capabilities of the body, enhancing its economic utility and ensuring its political docility."

(Hughes & Paterson, 1997, 332)

This distinction between economic productivity and political docility explains what at first seems a strange paradox; in a system that renders bodies docile and dependent, young people encouraged to meet up to the ideal of an active, independent, neoliberal subject. Bio-political systems of power-knowledge create economically productive, yet politically docile bodies. Furthermore:

“The ‘active citizen’ is the employed individual who, whilst committed to the pursuit of economic well-being, seeks to do good to others, but purely in a private capacity.”

(Barton, 1993, 244)

Barton above extrapolates neoliberalism’s bias towards a charity model of disability. Advocates of neoliberalism maintain that the ‘deserving poor’ and the ‘real needy’ will be looked after as prosperity generated from the markets is passed down through acts of private do-goodery. Thus, the state is rendered unnecessary. As it is now unnecessary, we are led to believe that with the destruction of the welfare state, the state disappears and is replaced by market forces. However, Giroux (2009) argues that, rather than the state disappearing, we see a shift in relations. The welfare state becomes the market state, and the state/citizen relationship becomes one of corporate/consumer. The state does not lose its power, but reconfigures it, putting responsibility and blame onto individuals. Rather than accounting for poverty, homelessness and joblessness as a failure of systems, individual suffering is assumed to be a result of personal failure and deficit (Giroux, 2009), all of which can be recognised in “the language of shirkers and scroungers” that surround disability (Garthwaite, 2011, 320).

Also recognisable in language surrounding the *Welfare to Work* programme is rhetoric of ‘custom’: claimants are not citizens, but customers. With this comes the connotation of ‘choice’ that is used to apply individual blame (Giroux, 2009). The story of the official textbook of neoliberalism is as follows. We all have a choice which we follow up with an action. Actions have consequences. As the consequence is only a result of individual choice, it is only the individual that it to blame (Barber, 2007; Barton, 1993; Giroux, 2009). As disability is considered a tragic biological fact (not a choice), disabled people require charity (Barton, 1993). However, there are the ‘unreasonable’ amongst us that claim to be, but are not really disabled, and these people need searching out (Garthwaite, 2011). When the financial budget is in a state, it seems the number of (real) disabled people significantly decreases, and the number of those masquerading as disabled increases.

**It is with deep regret that we announce,
Britain will NOT be represented in the
Paralympics this year...**



**As we appear to have nobody with a
Physical Disability.**

Figure 3: Photo created by Facebook group: “We demand David Cameron undergoes psychological assessment”

“Underpinning a system committed to the freedom of the market is a belief in *equality of opportunity to become unequal*” (Barton, 1993, 241, my emphasis). We are no longer citizens of the state, but customers of the market, and, like the customer entering a shop, we have a choice... but the choice has to be made out of what is already on the shelves and considered in relation to the money we already have in our pocket (Giroux, 2009). To be politically active in order to change the system is not a choice on offer.

“The consumer here is radically individualised rather than socially embedded, and less rather than more free as a consequence. She is permitted to choose from a menu of options offered by the world but not to alter or improve the menu or the world.”

(Barber, 2007, 36)

Wyn and White (1997, 94) argue that despite connotations of fluidity and change, young people’s transition to adulthood means them ‘choosing’ from a few very set routes to adulthood. Furthermore, for some, “the menu of the world” (Barber, 2007, 36) is shorter than for others. Disabled youth, I argue throughout my thesis, are offered a very limited

menu. To choose to fit into this system the young person must strive to be the economically productive adult ideal: entrepreneurial, financially self-sufficient and employed (Erevelles, 2002; Kelly, 2006). However, they also need to be politically docile: to be grownup one must be compromising, conservative, moderate, rational and silent (Allen, 1968; Burman, 2008a). These juxtapose connotations of active, volatile young people. However, neoliberalism also values the ‘youthful’ characteristics of speed and fluidity as qualities of adulthood (Blatterer, 2010; Hughes, et al., 2005), features Giroux sees as key to a consumer society:

“In this consumer society, the modern political and economic ambitions that stressed procrastination, delay, long-term investment, and durability have been replaced by an emphasis on speed, instant gratification, fluidity, and disposability.”

(Giroux, 2009, 36)

A consumer society is a fast-paced society with a fast-turnover of goods: we no longer value products of quality that will last, but want cheap, one-off products that we expect to quickly dispose of. Giroux (2009) maintains that consumption is not about possessions at all, but about disposing of them. Furthermore, in the consuming society the sovereignty of the consumer replaces the sovereignty of the citizen. The commodification of products therefore turns into the commodification of human beings. The perceived ‘value’ of a human being equates to their market-value: “in the society of consumers, no one can become a subject without first turning into a commodity” (Bauman cited in Giroux, 2009, 31). And, when people become commodities, people too are disposable.

The danger of disposability for disabled youth

A consumer society makes us all into commodities: a country’s success measured through Gross National Product; children encouraged to be entrepreneurial; the ‘active citizen’ not active at all, unless this activity happens within markets (Giroux, 2009). The marks of a good commodity: fluidity (the ability to constantly rebrand); speed (to keep in line with fast-turnovers); and, ultimately, marketability; the ‘youthful’ qualities of Youth for Sale that signify adulthood (Blatterer, 2010). Those that are not a commodity we wish to invest in are in danger of disposability within a consumer society. The neoliberal agenda of the coalition government encourages us to seek out and dispose of those who cannot/do not/will not constantly refashion and rebrand themselves. Research question

one asks what dangers young disabled people face if normative discourse remains unquestioned. Under the coalition government, disabled young people are in danger of becoming part of a disposable population.

We see therefore dangers of disabled and young people being construed as passive. The passive subject is one opposed to the ideal, neoliberal adult subject (Giroux, 2009; Kelly, 2006) and looking back at history we should be wary. We have seen the rhetoric of ‘the burden to society’ used before with devastating consequences, at the time of holocaust (Hughes, 2001). Giroux (2009, 2) deems neoliberal consumerism “economic Darwinism”. I maintain, however, that representations of disabled people as dependent, despite having very real consequences, are by no means ‘true’ representations. We see this clearly through my analysis over *Section Two* of the thesis. When it is taken into account that many of the cuts slash funding to the tools disabled people use to lead an ‘independent’ life (vehicles which allow them to get to work, personal assistance, and so on), the absurdity of such representation is illustrated. Furthermore, as Hughes (2001) points out, fighting for (and troubling our conceptions of) independence has been at the crux of disability activism. Disabled activists creating their own ‘unofficial textbooks’ of disability which in time influence/infiltrate/corrupt the official textbooks. I learn from young disabled people reconceptualising independence in *Chapter Seven*.

Under the rightist agenda, rather than considered socially constituted, autonomy has been fetishised into some biologically inherent; something you either do or do not have. For disabled youth, this is dangerous. In order to reposition dis/abled young people as active, a critique of the valued attributes of youth, adulthood, of the ‘active citizen’, of dependence and independence is vital. Thus, it is also important to address research question three which asks what disability and the lived-experiences of young disabled people can teach us about youth. I do this over *Section Two* alongside my young disabled participants.

Discussion

This chapter has addressed research question one, what dangers do young disabled people face if normative discourse remains unquestioned? I have highlighted the dangers young disabled people face if we fail to consider normative discourses of neoliberal adulthood. The ideal young person, I conclude at the end of this chapter, is one striving,

and on track to becoming, the ideal, neoliberal adult: the Mr Reasonable I addressed in my preface. Key to this is a focus on entrepreneurialism. They must be economically active (spending within markets), but with an eye on future economic activity/productivity (future employment prospects). In order to achieve in the game of the entrepreneurs they must be marketable. Popular on the market right now as features of the commodified subject are characteristics commonly paired with ‘youthfulness’: beauty, health, speed, fluidity. In current political climates those failing to meet the ideals of neoliberalism are left aside; the less-than-ideal human commodity disposed of.

Much of the transitions-based CDS research cited at the beginning of this chapter argues young disabled people are no different to other young people. They are active becoming-adults (Hendey & Pascall, 2002; Morris, 1999, 2002; Rabiee, et al., 2001). As I continue into my analysis chapters over *Section Two*, we see young disabled people making similar arguments. They want to be seen as independent (*Chapter Seven*), gendered and sexual beings (*Chapter Eight*). There is a timely and strategic place for research which argues young disabled people’s ‘sameness’, for the sake of survival. At the same time, however, we have a responsibility to question these markers of neoliberal adulthood for the sake of those who cannot/will not fit in. Markers, that I go on to argue, work to concrete disabled people as unproductive, dependent, eternal children. Research question two asks how disability researchers can share the stories of young disabled people in order to reposition them as active and politically resilient. This chapter has highlighted the importance of such a repositioning. We have seen the narrow definition of activity expected of the good neoliberal subject. Activity which is denied to disabled people as support allowing them to be the productive citizen is removed (Hughes, 2001). We therefore need to expand our notions of activity to include activity taking place outside the market; cultivate methodological thinking outside service provision; and engage with other disciplines doing youth research, to put disability on their agendas. Research questions three and four ask: what can disability and the lived-experiences of young disabled people teach us about youth? And what can youth and the lived-experiences of young disabled people teach us about disability? I maintain that the not-fitter-inners, those inhabiting the liminal spaces that are youth and disability, have a lot to teach us. Our job is to develop the theoretical and methodological tools to learn from disabled youth. Over *Section Two* I offer my own experimentations on this note. Now, however, I turn in *Chapter Three* to further explore the commodification of youth, through a gendered account of Youth for Sale.

Chapter Three

Youth for Sale and The Aesthetic Project of Youth

Introduction

“The ideal is to be adult and youthful but not adolescent”

(Blatterer, 2010, 74)

I continually assert that youth is more complicated than an age-bound period of life. In *Chapter Two* I argued that ‘youthfulness’ optimises a good market commodity: beauty, health, speed, fluidity (Giroux, 2009). In this chapter I explore gendered notions of Youth for Sale by considering how youth relates to the ‘body beautiful’. I call, therefore, on theories of commodification. Mallet and Runswick-Cole (2012) utilise theories of commodification in relation to autism. They attribute the prevalence of autism to processes of fetishisation (a Marxist concept of making something a ‘thing’ by distancing a product from its labours). They explore the commodification of autism by asking: who produces autism? What want is autism satisfying? And what is the promise of autism? According to dominant developmental theory, unlike autism, youth is a stage we all embody for a period of our lives (Burman, 2008a). However, youth stands for much more than just an age-bound period of life (Wyn & White, 1997). Hence, it is not immune from fetishisation and commodification (Burman, 2008a; Giroux, 2009). As feminist scholars have highlighted, there is a self-governing expectation, especially on women, to perform ‘body-work’ in order to meet up to an ideal of bodily perfection (Shalma, 2008). One of the aims of such body work is to retain a ‘youthful’ body (Featherstone, 1982; Heiss, 2011). The body becomes an aesthetic project, with youth as a desirable outcome.

I argue in this chapter that Youth for Sale abstracts youth into an expectation of normative adulthood, or, more specifically, womanhood. Such an abstraction, however, impacts upon young people’s lives. Drawing on Mallett and Runswick-Cole (2012), I thus ask, who produces Youth for Sale? What want does Youth for Sale satisfy? What is the promise of Youth for Sale? Featherstone (1982) argues that the aged body is inscribed with the passing of time, and we attempt to deny this in our attempts to embody ‘youthfulness’. CDS perspectives help me to unpick Featherstone’s arguments. I explore

notions of time more closely by engaging in both CDS discussions of ‘crip time’ and literature from the sociology of childhood which considers children’s understandings of time. Both schools of thought see embodiment as key to our conceptions of time. I therefore argue that the aesthetic project of youth links youth with not just beauty, but also health; health and beauty the want and promise of youth. These conceptions of ‘youthfulness’ exclude the lived-realities of young disabled women. This chapter therefore contextualises research question one, paying attention to the dangers young disabled women face when normative discourse remains unquestioned; arguments expanded upon in *Chapter Eight*.

Research question three asks: what can disability and the lived-experiences of young disabled people teach us about youth? Disability helps us in this chapter to more fully understand the construct of Youth for Sale. I therefore begin by outlining, and then utilising feminist-disability theory.

Feminist-disability theory

Uncovering youth as an aesthetic project begins with the recognition of the body as discursively and culturally inscribed with meaning (Butler, 1990; Garland-Thomson, 2002; Heiss, 2011; Meyer, 2002). During the 1990s examining the consequences of bodily representations became central to feminist theory (Garland-Thomson, 2002; Meyer, 2002). Scholars used feminist theory to explore the body in relation to gender, race, ethnicity, sexuality and class – asking how these medleys of identities meant some bodies were regarded more highly than others. However, despite the centrality of disability to experiences of embodiment (Shildrick, 2009), how dis/ability featured in discourses of the body was an area neglected by feminist theorists (Garland-Thomson, 2002). This silence cannot be entirely blamed on lack of feminist engagement. As outlined in the introductory chapter, the staunch social model focus of British DS, separating impairment (a difference, or perceived difference, of bodily function) and disability (subsequent oppression placed on disabled people by society) prohibited talk of the body (Crow, 2012). This was not without good reason, previous medical focus constructed the disabled body as deficient, in need of intervention, rehabilitation and, ultimately, extermination. Disabled people’s political struggles shifted the gaze from disabled bodies, to an oppressive, disabling society. Additionally, the lack of communication between feminist and disability theory could be attributed to the

pragmatism that few disability theorists ‘knew’ feminist theory, and few feminist theorists ‘knew’ disability theory (Garland-Thomson, 2002).

Embodiment, however, is re-entering discussions. Voices of disabled women highlighted the lack of space available for them within both feminist and disability movements (Crow, 2012; Morris, 1992, 1998; Thomas, 1999). They carved the way for feminist-disability theory. Whereas feminist theory forces us to re-examine assumptions concerning women, and disability theory challenges individualising conceptions of disability, feminist-disability theory brings the two together, not additively, but alongside further intersections of race, class, sexuality, and so on (Garland-Thomson, 2002). Feminist-disability theory sees disability, like gender, as a phenomenon spanning all aspects of life. Thus, feminist-disability theorists do not only address issues directly concerning disability, but critically engage with wider cultural phenomenon. As Garland-Thomson (2002, 4) puts it, “the cultural function of the disabled figure is to act as a synecdoche for all forms that culture deems non-normative”. Feminist-disability theory challenges what appears ‘natural’. Adding disability to the intersectional work already done by feminist scholars adds depth to a critique of idealised bodies. Feminist-disability theory is therefore helpful to uncover the dangers of Youth for Sale to disabled youth. I now utilise feminist-disability theory to critique cultural discourses of the ‘youthful’ dis/abled female body.

Positioning the dis/abled female body within the popular media

Idealised media representations of the body have allowed unattainable images to become normal standards of beauty (Garland-Thomson, 2002; Shalma, 2008; Soley-Beltran, 2004). This has resulted in an ethos of personal responsibility (Featherstone, 1982; Shalma, 2008). Featherstone (1982) and Turner (1993) argue that discourses of dietary management exemplify ‘disciplining technologies’; encouraging an ethos of self-discipline in order to meet up to expected bodily standards. Studies show the negative impact this has on women and girls, attributing the prevalence of anorexia and bulimia, for example, to the pressure to conform to unattainable bodily ideals (Bordo, 1993; Fallon, Katzman, & Wooley, 1994). Hassouneh-Phillips and McNeff (2005) argue that these images can be particularly harmful for disabled women (discussed further in *Chapter Eight*). One expectation is to retain a ‘youthful’ body (Heiss, 2011).

That youth is a commonly recurring feature of the idealised body becomes anecdotally apparent when considering the number of products available on the market claiming to prolong youthful looks. The invisibility of older people within the advertisement industry has been noted (Carrigan & Szmigin, 2000). An article appearing in *The Guardian* in 2010, however, claimed that “the fashion industry is over its obsession with youth” (Cartner-Morley, 2010), before going on to support this with a list of ‘older’ women being used in advertising campaigns (the oldest being Madonna, at aged 51, modelling for *Dolce and Gabbana*). *The Guardian* is not unique in now hosting a fashion column in its Saturday magazine supplement sporting ‘all ages’ models. Furthermore, popular make-over television shows such as, *How to Look Good Naked*, a programme claiming to show “women how to look fantastic with their clothes on or off no matter what their body shape - and all without a surgeon's scalpel in sight” (Channel 4, 2011b), have been accredited within the popular media with challenging notions of idealised feminine beauty, and lessening the pressure to conform to such an ideal through cosmetic surgery. The show’s presenter, Gok Wan, also endorsed the UK strand of the *Dove Campaign for Real Beauty*. Attributing the media as the main cause of bodily unhappiness, the campaign aimed to counter dominant notions of feminine beauty to “ensure that the next generation [of young women] grows up into happy and content adults, free from misconstrued beauty stereotypes and the burden of self-doubt” (Dove, 2011).

There are now popular television reality shows aiming to bring disability into the realms of the ‘beautiful’. 2009 saw the BBC’s *Britain’s Missing Top Model*, a spin off *Britain’s Next Top Model* (itself the British sister of an American counterpart), pit disabled women against each other to win a modelling contract. The following year, *Channel 4* produced a spin off version of ‘*How to Look Good Naked*’, entitled, ‘*How to Look Good Naked... with a Difference*’. Three programmes subjecting disabled women to the public undressing and stylistic tips of Gok Wan. *Channel 4* later went on to produce *Beauty and the Beast: The Ugly Face of Prejudice*. This six part series, endorsed by the facial disfigurement charity, *Changing Faces*, attempted to “investigate the extremes of discrimination”. Each episode brought together one ‘beauty’ (a person “preoccupied with their appearance”) and one ‘beast’ (a person with a “facial disfigurement”) in an attempt to challenge dominant notions of beauty (Channel 4, 2011a). For all these series disability was the hook, drawing us in by asking us to gaze upon the disabled body. When disability appears within our mainstream media without ‘warning’, or not as a ‘feature’, the audience reception is less favourable. This became shockingly apparent

when the *BBC* chose Carrie Burnell, a young, conventionally ‘attractive’, disabled woman, able to ‘pass’ as acceptable by most beauty standards if it was not for the ‘missing’ lower portion of her right arm, to present their children’s television channel *CBeebies*. A move which resulted in complaints from parents claiming Burnell was “scaring their children” (Mangan, 2009). The same year, a 22-year-old shop-assistant sued designer fashion label *Abercrombie and Finch* after they insisted she moved from working on the shop floor to the stockroom, claiming her prosthetic arm did not fit their image (BBC News, 2009). Furthermore, when US fashion magazine, *Glamour*, published a 7.5cm, un-airbrushed photograph of ‘plus size’ (yet young, attractive, blond, and with no visible impairment) model Lizzie Miller with a small roll of fat around her stomach, the generated media frenzy was phenomenal (Sanie, 2009).

From the above examples *The Dove Campaign for Real Beauty* claims to work towards wider social change. As well as using women who would not meet conventional ‘modelling standards’ in their adverts, *Dove* also launched *The Self-Esteem Fund* and encouraged audiences to participate in its campaign through its interactive website. Heiss (2011) uses feminist-disability theory to engage with the campaign. She argues that *Dove* does not go far enough in its attempts to include a diverse range of female bodies, instead acting within “an ideology of naïve integration”. That is, an ideology that rhetorically insists upon a respect for diversity, yet, in reality, results in tokenism; (re)inscribing dominant notions of the ‘normal’, ‘beautiful’ and idealised ‘feminine’ body. Not only does *Dove* not use a model with a visible impairment, those models that are used could ‘pass’ as traditional models, albeit for one feature. Heiss (2011) maintains, for example, that the ‘fat’ model “hardly looked overweight” and, apart from grey hair and a few wrinkles on her face, the body of the ‘older’ model “could have been that of any typical fashion model and was unrepresentative of many women”. Similar criticisms could be made of the shows cited above. The winner of *Britain’s Missing Top Model* could have ‘passed’ as any other model if it was not for her ‘missing’ forearm. Interestingly, although celebrated in this show, this is the same impairment that caused such controversy in relation to the *BBC*’s children’s television presenter when disability was not the ‘hook’. Furthermore, *Dove* insisted we look upon women’s bodies as “separate parts to be examined” (Heiss, 2011). Rather than viewing the women holistically the models were separated by discrepancy from ‘modelling standards’: the ‘old’ model, the ‘fat’ model, the ‘freckled’ model, and so on. Heiss (2011) insists that this is dangerous:

“Because the campaign was situated as a safe place for social change, when the campaign suggested that women should gaze upon and evaluate the body it reified beliefs that objectifying the body is acceptable and natural”

(Heiss, 2011)

Heiss (2011) argues that, despite claiming to challenging the objectification of women, *Dove* reifies an objectifying gaze. Rather than delivering celebratory messages of diversity to, amongst others, disabled youth, normativity prevails.

Garland-Thomson (2002), however, complicates arguments of objectification in relation to disability. She highlights that images of disabled people traditionally fall into four categories: charity advertisement, freak show exhibits, medical depictions or “sensational and forbidden pictures” (Garland-Thomson, 2002, 23). With disability sometimes comes an assumption of asexuality, therefore, the gaze placed upon disabled women is not one of (explicit) sexual objectification but one of medical spectacle. Disabled women should be allowed the same “freedom to be appropriated by consumer culture” that non-disabled women have, even if this means increased sexual objectification, as, “to reject this paradoxical liberty is one thing; not to be granted it is another” (Garland-Thomson, 2002, 24). We see in *Chapter Eight*, that some young disabled women whom I spent time with agree with Garland-Thomson. This is not to dismiss Heiss’ (2011) important point that *Dove* does not go far enough in including a diverse range of female bodies. Nor is it a call to reject critical engagement with such imagery. Rather, Garland-Thomson’s (2002) analysis highlights the additional level of scrutiny a feminist-disability perspective allows for. Whereas a purely feminist analysis may dismiss programmes such as *Britain’s Missing Top Model* as reifying the sexual exploitation of women, a feminist-disability perspective considers the complex histories and intersections between gazed upon disabled and female bodies.

Interestingly, in *Dove*’s campaign and the other non-disability specific texts claiming to challenge dominant discourses of beauty, there is an emphasis on the ‘normal’ or the ‘average’ woman replacing the ‘spectacular’ or ‘extraordinary’ model. Heiss (2011) herself points to the discrepancy between the weights of models compared to the “average female” and writes of “narrow representations [of bodies that] have led to individual and societal dissatisfaction with the actual lived bodies that comprise *most* of the public” (my emphasis). This approach is perhaps justified to re-appropriate what we view as ‘normal’. Discourses of beauty and medicine have worked together to make

unmodified bodies appear unnatural and abnormal, whereas those that have been surgically altered (whether through reconstructive or cosmetic surgery) are conceived to be natural and normal (Garland-Thomson, 2002; Heiss, 2011; Shalma, 2008; Soley-Beltran, 2004). Models, Soley-Beltran argues, act as a figurehead to these normalising discourses of power-knowledge:

“By embodying alleged physical perfection and permanent self-confidence, models’ images and public personas make us believe in the utopian possibility of avoiding the discredit and abjection that menaces many women for not conforming to aesthetic and behavioural norms.”

(Soley-Beltran, 2004, 37)

Images of ‘perfection’ mean we falsely believe in the normality of modelling conventions, and place an expectation on women to comply with these perceived norms. This explains the disproportionate interest when *Glamour* magazine chose to use a model with a stomach not meeting modelling convention. However, when such minute differences provoke such frenzied attention, we can only imagine the extrapolated responses that would be evoked if, without warning, a body further from this pseudo-norm was employed. Research question one asks what dangers young disabled people face if normative discourse remains unquestioned. We begin to see how normalised discourses of Youth for Sale function to Other disabled youth (discussed further in *Chapter Eight*). Furthermore, it seems reclaiming normality does not stretch as far as those ‘differently-embodied’ (Shildrick, 2009). Despite supposed similar aims of challenging bodily ideals, when campaigns focus specifically on disability, the discourse of ‘normal’ moves to one of ‘difference’ (illustrated by the shift from *How to Look Good Naked* to *How to Look Good Naked...With a Difference*). We are not incorporating the bodies of ‘normal’ women, but the bodies of ‘different’ women into notions of beauty. The focus shifts from reclaiming normality to appreciating diversity.

Drawing on both personal experience as a model and empirical data from research, Soley-Beltran (2004, 40) writes that although models are “a mechanism defining and regulating the normative standards of acceptable identity”, there is also a ‘fascination’ surrounding them. Models are simultaneously “the object of envy” but also “alienated from [their] own image [and] considered unreal or intellectually handicapped [*sic*]” (Soley-Beltran, 2004, 40). Although she does not specifically use the term ‘freak’, Soley-Beltran’s (2004) discussion of feminine beauty hints at an ‘enfreakment’ of models – objectified, gazed upon, at once the objects envy and disgust, and their bodies read as a

signs of their intelligence (Hevey, 1992). Although perhaps the beauty standards models embody have been encompassed to become a ‘normal’ part of society, the models that embody them are read as ‘abnormal’ – and judgements about their mind, made from the surface of their body.

Other feminist theorists have recognised that ‘character’ and ‘state-of-mind’ judgements are made from surveying the female body (Grosz, 1994). Furthermore, feminist-disability scholars have highlighted the additional gaze placed upon the bodies of disabled women (and, to a lesser extent, men). Shildrick (2009) notes that when the body is normative, Western discourse separates mind and body as wholly separate entities; the mind privileged as free, rational and disembodied. Yet when the body is marked as ‘different’ the mind is also considered ‘damaged’. Such a reading of the body can result in infantilising disabled people, but also, following the logic of Soley-Beltran (2004), all those whose bodies we consider ‘different’ – even if this is a difference we are encouraged to aspire to. As ‘youthfulness’ is an expectation of the ideal body, youth becomes equated with bodily perfection. The aesthetic project of youth, therefore, is one of meeting the modelling body conventions; youth comes to *stand for*, the tall, the slim, the ‘beautiful’. Youth is abstracted from young people’s lived-realities. Arguably, this is especially the case for disabled youth. Soley-Beltran’s (2004) argument, that there is both envy and an ‘enfreakment’ of models, can here be applied to youth. Although youth is a desirable outcome of the aesthetic project we are encouraged to set out upon, this does not mean young people themselves are positioned as ‘ideal’. Youth for Sale leads the enfreakment of non-normative youth, including disabled young people. Although the ideal body is always young, the young body is not always ideal.

Youth, embodiment and time

“Scholars have found that images of the body often present idealized versions of feminine beauty – thin, tall, long legged, and always young”

(Heiss, 2011)

Although having a ‘young’ body is ideal, when used in this way, the terms ‘young’ and ‘youthful’ represent something very different to the lived-experiences of chronologically young people. Youth for Sale is contradictory to other discourses of youth (Youth as Active and Youth as Passive). When considering those chronologically young the

emphasis is on temporality: youth is the period after childhood and prior to adulthood; a time it is desirable to ‘grow out of’ by meeting the adulthood signifiers. Youth and time are therefore intrinsically, yet incongruously linked. Whereas, on the one hand, we want to assist our young people in their risky transition to adulthood (the sooner they reach adulthood the better), there is also a desire to remain, as adults, forever young. Although when discussed *explicitly* youth is about transience, when discursively, perhaps *implicitly* used, youth is about the desire to pause time. I have highlighted over the last two chapters the ableism inherent to a discourse of youth as becoming-adult. It seems neither of these youth-time relationships is useful for disabled youth. As my young disabled participants confirm in *Chapter Eight*, Youth for Sale excludes the lives of young disabled people. It is therefore important to continue exploring the potential dangers Youth for Sale poses to disabled youth. I want to know what else we aspire to when we strive towards the embodiment of Youth for Sale; what is the promise of youth? Discussions thus far tell us that time and embodiment are key features of our desire for eternal youth. I now step away from direct encounters with youth for a while, in order to consider relationships between time and embodiment further. I bring youth back in the latter part of discussion.

In a neoliberal society, time is a valuable commodity. Christensen, James and Jenks (2001) consider how children understand and embody time, arguing that children learn the ‘value’ of time through bodily discipline in the classroom. ‘Wasting’ the teacher’s curriculum time, leads to the teacher claiming back this time by denying the student playtime. Children learn that time is a finite resource, to be used productively: ‘time is money’, not something to be ‘wasted’. If used correctly, the reward may be ‘free time’. According to budget studies of time, this means a better quality of life (Adam, 1990). How time is used in the present leads to consequences in the future, something children and young people (incomplete-adults), know all too well – work hard in school, and you will be rewarded with a good job (an essential of adulthood), or so the story goes. Featherstone (1982) argues that the aged body is inscribed with the passing of time which serves as a reminder of our own mortality. This, he argues, is something we try to disguise through body work, maintenance and repair. Whereas children and young people are encouraged to use their time productively in order to ensure a ‘good’ future, our desire for youthful looks is perhaps a desire to put off mortality, to suspend time. To again quote Blatterer (2010, 69), “the ideal is to be adult and youthful but not adolescent”.

Embodiment is imperative to conceptions of time. Time, embodiment and time's ability to include and exclude is explored within CDS. Resting upon the argument that disability is not 'fact' but a social construction, Ferris (2010) argues that disability is always mediated, and that "one crucial mediation of it, is time". Neither is time a 'fact'. Michalko (2010) writes of "culture standard time" - the time we are all expected to adhere to, the time of the normates, the ideals, the 'ordinary man'. As a blind man, Michalko writes of "feeling dorky" using a white cane to navigate his way around (a risk, he maintains, we all face when entering a different time zone); although 'blind time' and 'culture standard time' are expected to be in synchrony with one-another, the assumption of sightedness means a blind person acting within 'culture standard time' risks of "looking dorky". Nevertheless, blind people are expected to 'fit in', to synchronise their watches with 'culture standard time'. Refusing to do that, however, blindness time offers, a "time for sight, for normalcy, to develop self-understanding" (Michalko, 2010). Similar notions have been maintained by others under the term 'crip time'. 'Crip time' is not just about allowing extra time, working within a discourse of inclusion which also allows for exclusion (Price, 2011; Titchkosky, 2007, 2010), but about flexibility and the questioning of normative and ableist time frames (Price, 2011). Again, disability illuminates and allows us to challenge what has become inherent. I show young people in *Chapter Six* claiming back their own time, from time frames imposed upon them.

Classrooms are a stark example of largely unquestioned normative timeframes, which add to the educational exclusion of disabled children (Price, 2011). As Davis and Watson (2001, 674) put it, the disabled "child is forced to fit into already existing educational and social processes and practices, which afford little space for the investigation or understanding of difference". Although not specifically engaging with disability, James (2000) points to the continued influence of developmental psychologists such as Piaget in the structuring of children's lives. She argues that children's bodies are defined by the passing of time; such as schools being organised into age-based classes. Thinking back to *Chapter One*, we see assumptions of normative development potentially excluding disabled children. However, she highlights that children do not understand the relationship between their bodies and time as purely quantitative. Rather, age (the measure of time we apply to living things) is conceptualised as a holistic, embodied experience, which symbolises social status, and allows or denies access to any number of

endeavours. The following quote from James' fieldwork with primary aged children illustrates this:

“CAROL: (after comparing her height to Lorna) I'm bigger

ALLISON [researcher]: Would you like to be tall?

CAROL: Yeah... I want to be 15

ARTHUR: Your birthday is before mine

GEORGE: Yeah, I'll be 6 and I'll be bigger than you then”

(James, 2000, 29)

Children learn their bodies through the passing of time. The discussion of time, therefore, leads to one of bodies. Aging is interwoven with normative ideas of bodily capability. As well as learning that time has a 'value' in the classroom, children also get taught that a 'good' body is “both controlled and seen to be controllable” (James, 2000, 31). The 'good' student in the classroom walks properly, sits up straight, doesn't fidget, ties her shoelaces and tucks in her shirt. Davis and Watson (2001) report that physical restraint is routinely used in classrooms to ensure the conformity of disabled children's bodies. Furthermore, the older the child is, the closer she is to 'youth', the higher the expectation of a 'good' classroom body (James, 2000). In concurrence with feminist-disability critiques of idealised bodies, we see that the process of judging the interior of the body by its exterior begins in school, and children are aware of this (Backett-Milburn, 2000; Burnett & Holmes, 2001; Christensen, 2000). Discourses of 'good' bodies work alongside those of 'normal' and 'healthy' bodies. Through these discourses children learn the cultural importance of body work. James (2000) explains with the example of children's conception of a 'fat' body. A fat body is a greedy body that is not properly controlled. Bodies must be orderly. A fat body cannot tie its shoelaces or walk properly, so it's not a good orderly classroom body. Bodies must also be able to participate. A fat body cannot run fast, it gets caught playing tig. It is not a good participating playground body. Fat bodies, like disabled bodies, are undesirable. Children, like adults, James (2000) argues, judge bodies in moral terms, although a tall body signifies age and maturity, a fat body is equated with lack of bodily control, greed and antisocial behaviour. Disabled children's bodies are undesirable to the extent that they endure the violence of routine physical correction (Davis and Watson, 2001). Again, we see the importance of research question one: what dangers do young disabled people face if normative discourse remains unquestioned? As Barton (1993, 243) puts it, “[p]hysical difference [...] makes the bodies of disabled people public property”.

Literature considering the sociology of the body and the sociology of childhood has scarcely engaged with disability and experiences of disabled bodies (Shakespeare, 2006b; Wickenden, 2010). Chandler (2010) approaches the body through a CDS perspective when she writes about her Mum telling her, her ‘first story of disability’:

“My story of her story goes like this: When I was 5 years old I went to a friend's birthday party at the zoo. A group of girls were showing off their newly discovered skill of doing a cartwheel. As I began the dismount into this ellipse, I expected to complete it without trouble like the girls before me. Instead of gracefully spinning forward as was previously demonstrated by my friends, my wrists buckled under my weight, my legs refused to fly upwards, and I collapsed in a laughable heap on the grass in front of them. In this moment I understood my body as troubling but I did not have an idea of, and thusly did not have, a disability. Later that night, as my mom was helping me get ready for bed, I asked: "Mom, why can't I do a cartwheel?" expecting she would be able to untangle the entanglement that was my experience of my embodiment. She responded with the first telling of disability.”

(Chandler, 2010)

Chandler’s story illustrates time’s mediation of disability (Ferris, 2010). She was not disabled until after she had “understood her body as troubling”, at which time she was told of disability. Chandler’s story also shows that disability’s invisibility within the sociology of the body and childhood is conspicuous. When Davis and Watson (2001) highlight the physical restraint disabled children face when not conforming to normative time/embodiment frameworks, we see how replacing James’ (2000) explorations of children’s conceptions of ‘fat’ bodies with disabled bodies could result in potentially more demonising conceptions. Moreover, as much research considering time/embodiment relationships stems from CDS and the sociology of childhood, it seems children and disabled people are perhaps more enlightened than their adult and non-disabled counterparts in realising the exclusionary potential of this time/embodiment relationship. When I ask my young disabled participants about time and embodiment in *Section Two*, we see the importance of listening to those at the peripheries (Shildrick, 2004).

Let us link this back to Youth for Sale. I argued earlier that discourses of Youth for Sale result in women’s minds being ‘read’ from the exteriors of their bodies. This is particularly the case when the women are considered ‘differently embodied’ (Shildrick, 2009). Christensen’s (2000) exploration of cultural constructions of childhood

vulnerability and Backett-Milburn's (2000) study of adult and child perceptions of 'healthy bodies' concur with James' (2000) arguments around 'fat' bodies. Children, like adults, make internal judgements about a person, based on their external appearance. Furthermore, both children and adults are aware of the importance of 'body work' in order to maintain healthy (read: 'controlled', 'orderly', 'moral', 'good') bodies. For adults 'body work' is done self-consciously in order to meet expectations imposed by Youth for Sale, and both under and over attention to bodily maintenance is open to criticism. For children, however, the reasons are more pragmatic: "exercise had strong and immediate purposes of social inclusion, pleasure, personal credibility and peer acceptance" (Backett-Milburn, 2000, 97). A well exercised body can take part. It does not get caught in tigs. It can do cartwheels. Furthermore, a well-presented child's body is seen as a sign of adult parental achievement (Christensen, 2000). Although the ideal body may always be young, the young, like the aged body, is expected to work to meet ideals.

Youth means beauty means health

Let me consolidate my arguments, and explain how they help to contextualise research question one: what dangers do young disabled people face if normative discourse remains unquestioned? From the above discussion it seems that children and adults are equally aware of an expectation of self-governance and duty of bodily care. As feminist critiques of fashion industry showed earlier, young people (sitting somewhere between child and adult) are far from being outside of these disciplining discourses. For adults, there is an expectation not to just govern their own bodies, but to maintain the bodies of their children, and encourage children to carry out their own body work. Children come to know, judge and rate their own and each other's bodies (and minds) by their external appearance. A discourse of 'time' also permeates: whereas children's bodies are conceived to age positively (getting bigger and stronger), adult's bodies age negatively (becoming more susceptible to serious illness and losing capabilities) (Backett-Milburn, 2000). The older the body, the stronger the discourse of economic, social and physical decline (Biggs & Powell, 2001). Somewhere between the two is the ideal: an ideal children strive for in their growing *up* (bigger, taller, stronger) and adults strive for in their attempts to pause time (through purchasing anti-ageing, 'beautifying' products); the ideal of a youthful body, which I refer to as Youth for Sale. We are left, therefore, with three intertwining discourses: those of youth, beauty and health. As was previously

discussed, bodily maintenance is about standards of *beauty*. Yet, children and young people are taught that performing body work is a matter of *health*. Health, however, discursively stands for and implicitly comes to mean, much more than just the efficient functioning of body parts. If, as Garland-Thomson (2002, 4) argues, disability acts “as a synecdoche for all forms that culture deems non-normative”, Youth for Sale makes youth a synecdoche for both health and beauty – forms that culture dangerously deems normative.

If Youth for Sale signifies the idealised, normative qualities of youth, where does this leave non-normative youth? If to be youthful is to be beautiful and healthy, what does this mean for disabled young people? Despite the old cliché, ‘beauty is in the eye of the beholder’, we have seen that there are strong cultural conventions around what is ‘beautiful’. This, combined with arguably even stronger medical and cultural discourses about what is ‘healthy’ leaves those ‘differently embodied’ (Shildrick, 2009) paradoxically positioned. Although adulthood is wrapped up in ableist rhetoric, which alongside an ideology of paternalism leads to the infantilising of disabled people; there is simultaneously an idealised discourse of youth which leaves little space for human diversity. Baron, Riddell and Wilson (1999) quip that disabled people hold the secret of eternal youth. In this sense, disability is perhaps the counterpart of Blatterer’s (2010) ideal of being youthful, but not adolescent. CDS scholars have highlighted that we will all become disabled if we live long enough (Davis, 2002; Garland-Thomson, 2002). Take this assertion alongside Featherstone’s (1982) argument that strives for a youthful body attempt to deny our own mortality, and we could argue that the desire for eternal youth is an attempt to disavow disability. Of course, this is not the lived reality of dis/abled young people’s lives rather it highlights the abstraction of youth, leading to the enfreakment of young people that do not meet the conventions of Youth for Sale. Youth for Sale as a synecdoche for health and beauty. Health and beauty perhaps the promise and want of youth that we are encouraged to strive for in our own aesthetic projects.

Discussion

Research question one asks, what dangers do young disabled people face if normative discourse remains unquestioned? Although in this chapter I have not detailed *specific* dangers young disabled people face if we do not challenge discourses of Youth for Sale, the potentially exclusionary nature of the discourse has been illuminated. We have seen

that youth has been abstracted into a commodity to be sold in beauty markets. Hughes et al. (2005, 13) warn us that although “youth and its signifiers will sell, disability will not”. Considering youth as the end goal of an aesthetic project, I have drawn on feminist-disability discussions of idealised bodies to argue that discourses of Youth for Sale (read, beauty and health) stand in opposition to those of disability. At the beginning of the paper I drew on the work of Mallett and Runswick-Cole (2012) to ask three questions of youth: who produces youth? What want is youth satisfying? What is the promise of youth? I argue that beauty and related markets are one producer of the youth-thing. The want of these industries is profit. They satisfy this want by maintaining an unattainable ideal which they claim can be bought through their products. Youth for Sale has come to represent this ideal. Both mind and quality of life judgements are made from the exterior of the body. Meeting the youth-ideal, therefore, promises not just beauty, but also health and ‘the good life’. Youth in this thing-like-form is both oppressive and dangerous, marking bodies (and minds) that do not meet the youth-ideal as deficient, deviant and, thinking back to *Chapter Two*, disposable. Disabled bodies perhaps the most deficient, deviant and disposable of them all. Furthermore, when youth means beauty means health, there comes an added expectation on those who are chronologically young to comply with this, and an enfreakment of those who do not/cannot/will not – an expectation that can prove fatal (Bordo, 1993; Fallon, et al., 1994). In *Chapter Eight* I consider the dangerous lived-realities of Youth for Sale for disabled young women.

We have also seen, however, that Youth as Active and Youth as Passive are different constructs of youth, with different discourses at work in their production. Furthermore, the situation of disabled youth, I argue in the next chapter and throughout *Section Two*, can offer us other ways of thinking about youth, adulthood, disability, and myriads of other intersectional identities. I now go on in *Chapter Four*, therefore, to consider how, thought together youth and disability help me to address research questions three and four: what can disability and the lived-experiences of young disabled people teach us about youth? And what can youth and the lived-experiences of young disabled people teach us about disability?

Chapter Four

Is Youth Queer? Disability, Youth as Active and Productive Possibility

Introduction

In November 2010 an early draft of *Chapter One* formed my first presentation as a PhD student. Fearing difficult questions from the audience, I cleverly turned the tables, posing my own question: ‘is youth queer?’ One response was, ‘no, youth isn’t queer. Queer, should be left as a term for gay movements to use as a political tool; young people can find their own language to fight their own oppression’. This seemed oppositional to intersectional work. Furthermore, as outlined below, queer theory developed as a ‘binary breaker’, questioning the boxing in of non-normative sexuality. Restricting its use to the realms of sexuality seemed contradictory. The situation taught me the delicate nature of borrowing from other disciplines and movements. To justify utilising queer in my thinking around youth, I needed to explain what I mean when asking, ‘is youth queer?’

I introduced queer theory in the introductory chapter. Following Hughes et al. (2012), I argued the importance of employing theories as and when they appeared useful for my political purpose. Considering research question one, what dangers young disabled people face if normative discourse remains unquestioned, in *Chapter Two* I highlighted the dangers for disabled youth construed as passive. This justified research question two, finding ways, as disability researchers, to share the stories of young disabled people in order to reposition them as active and politically resilient. Research question two is both theoretical and method/ological. I assume young disabled people’s activity, and ask how researchers can demonstrate this activity through our theoretical and method/ological pursuits. What disciplines and theories could it be helpful for youth and disability researchers to utilise? This chapter offers a ‘theoretical romp’ through queer, postcolonial and Deleuzian theories. I do not claim to be an expert in the theories, yet ‘plundering as method’ (Hughes, et al., 2012), dip in and out of them to think about youth and disability. I argue that these theories, like CDS, and the phenomena of youth and disability, hold the potential to break down individualistic doctrines and self/Other binaries. Over *Section Two* queer, postcolonial and Deleuzoguattarian theories help me play upon the liminality

and ‘becoming’ status of youth and disability, to theoretically ‘unhook’ the transiency that surrounds youth from one of becoming-adult, to one which helps us appreciate the numerous different ways of becoming-in-the-world-together (Shildrick, 2009). Thus they enable me to answer research questions three and four: what can disability and the lived-experiences of young disabled people teach us about youth? And what can youth and the lived-experiences of young disabled people teach us about disability?

I begin by exploring the (sometimes strategic) dichotomies created by identity political movements. I outline debates roused by a move away from identity politics and towards an intersectional approach to activism and academia, specifically in relation to disability and sexual studies/politics. CDS and queer theorists have been accredited with/accused of (depending which camp you sit in) disturbing naturalised identity categories. I recount how realising my own engrained assumptions around childhood led me to postcolonial theory. Postcolonial theory has disrupted self/Other relations. In this chapter, I use it to consider the ‘inbetweenness’ of youth and disability. I draw particularly on Bhabha’s (1984, 1994) concepts of mimicry and hybridity to argue that youth and disability similarly disturb the stability of self/Other relations; a disturbance, I will argue, that can offer positive, queering potential. Concluding this chapter, I explain how Deleuzoguattarian concepts of ‘becoming’ and ‘milieu’ help me think-through youth, disability, and the embodied-lived experiences of disabled youth over *Section Two*.

Identity politics, queer theory and CDS

“[...] as soon as one perceives a monster [...] one begins to domesticate it, one begins [...] to compare it to the norms, to analyze it, consequently to master whatever could be terrifying in this figure”

(Derrida cited in Shildrick, 2009, 121)

Categorising people into specific populations attempts to create order within perceived disorder. Although it is asserted that the cultural category of ‘youth’ is a post-war concept reflecting changing political circumstances, the scientific/psychological category of ‘adolescence’ was already a widely accepted ‘biological reality’ (Bennett, 2008; Berk, 2010) (see *Chapter One*). Previous chapters show that attempting to categorise and define youth results in messy discourses of youth.

Foucault (1979) explores the process of categorisation. As introduced in *Chapter Two*, Foucault argues that nineteenth-century moves from punishing to disciplinary power meant not only increased and new forms of power-knowledge about individuals, but also “[g]overnments perceive[ing] that they were not dealing simply with subjects, or even with a “people,” but with a “population”” (Foucault in Rouse, 2007, 101). Rather than emancipate, Foucault maintained that liberal policies concerning constituted populations were a technique of power, leading us further into a surveying society (Rouse, 2007). Shildrick relates these arguments to disability:

“In focusing on singular behaviour, the state-sponsored model of disability promotes individuals failing above any attention to environmental factors. The DLA pack rigidly constructs and controls the definitional parameters of what constitutes disability in such a way that those who need to place themselves within that definition are obliged to take personal responsibility in turning a critical gaze upon their own bodies... power/knowledge relies on self-surveillance”.

(Shildrick, 1997, 51)

Once a label is given, the label can be normalised and made ‘safe’. Categorisation is therefore an attempt to order and control. Foucault (1977) also teaches us, however, that power is not linear, but cyclic: power and knowledge inseparable; nobody outside power-knowledge. Power-knowledge discourses are not imposed top-down but “co-constituted by those who support and resist” (Rouse, 2007, 112). We saw in *Chapter Three* that one producer of the ‘youth-thing’ was the beauty industry. Yet, we learnt in *Chapter One* that they are not the sole producer of youth: the media and politicians, for example, create other discourses of youth; and young people resist and define youth in their own terms (Bennett, 2008). Similarly, disabled people are continuing to challenge dominant discourses of disability (Hughes, 2001). Research question three asks what disability and the lived-experiences of young disabled people can teach us about youth, and research question four wonders what youth and the lived-experiences of young disabled people teach us about disability. We see throughout *Section Two* that young disabled people, living at the intersection at youth and disability help me to answer both these questions as they reshape discourses of both youth and disability. Labels also make up the artillery of the resistance. Essential to the game of identity politics is an identity to base politics upon. We are left in a paradoxical situation; although there is a politically strategic necessity for the public recognition of identity labels, such categorisation at the same time, leads to dangerous pathologisation (Shildrick, 2009).

My own research situated within CDS is illustrative of these debates within British DS. The social model separation of impairment (a physical, sensory or intellectual difference) and disability (societal oppression placed upon disabled people) brought disability into the world of identity politics: making disability an identity on which to base political struggles upon (Davis, 2002). I follow others, however, in stepping away from the British social model approach to research. My postconventionalist approach moves away from grand narratives to rather question what we take as 'natural', including disabled/non-disabled binaries. Arguably, this means the loss, or at least dilution, of a 'disability identity'. Whereas an identity political approach to 'youth' and 'disability' would focus predominantly on the material barriers young disabled people face in their transition to adulthood, research questions three and four require me to use disability to disrupt discourses of youth, youth to trouble conceptions of disability, and both to help us rethink how we live in the world (see *Chapter Two*). Critics worry, however, that by deconstructing naturalised assumptions around disability/impairment and exposing the myth of the 'able-body', CDS is denying the reality of the oppression of disabled people's lives and losing its value as a political tool.

A similar poststructuralist turn is visible in lesbian, gay, bisexual and transgender (LGBT) politics. The 1980s saw horrific losses of life as the AIDs crisis hit. In the face of government apathy and increased homophobic stigmatisation, previously fractioned LGBT groups came together to demand public recognition (Hall, 2003). Queer juxtaposed fine distinctions made between 'non-normative' sexualities and celebrated difference from the status quo, whilst simultaneously attacking the existence of a status quo. This was displayed through a new wave of 'in your face' activism; from flamboyant drag acts to public kiss-ins (McRuer, 2006). The word from the street was clear: 'we're here, we're queer, get used to it'. Queer's infiltration into the academy, however, was not immediate. A decade later queer theorisations began in cultural studies and English departments, adding depth and credence to what was happening on the streets (Hall, 2003). Drawing on feminisms animosity towards the natural status given to gender, queer theory theoretically addressed, questioned and disrupted heteronormativity alongside the flamboyant dressing up it was receiving from activists. Queer became the term that allowed movements to begin working at the site of ontology: sexuality, they argued, was not just a pleasurable bonus, but an everyday part of being human (Case, 1991); diverse sexual desire an intrinsic part of life. Queer attacked natural/unnatural dichotomies, defined boundaries and transgressed categories.

Yet, like concerns around CDS, critics worried that queer left LGBT movements with little identity to base identity politics upon (Hall, 2003). Furthermore, by rejecting the categorisation of sexuality, the terms queer and queer theory themselves resisted containment – being utilised outside LGBT politics (Shildrick, 2009). Whereas the aggressive queering of naturalised categories can, on the one hand, result in broad allegiances between oppressed groups, some worried that it was leading to a dilution of the very movements queer came about to enhance. These concerns again relate to CDS. Davis (2002), for example, warns us that when doing intersectional work, it's all too easy, yet unhelpful, to declare 'we are all disabled': women, disabled by a patriarchal society; people of colour, disabled by a racist society; gay people, disabled by a homophobic society. The potential delicate nature of borrowing from other disciplines can be seen in the 'is youth queer?' question outlined earlier.

Yet queer has been utilised in other transformative contexts. Sherry (2004) and McRuer (2006) utilise queer theory within CDS. Queer theory has also broadened to include experiences of race, ethnicity and, more recently, embodiment (Shildrick, 2009). Are these expansions further diluting a movement, or playing upon and creating allegiances? Is bringing queer into disability diluting political movements? If so, which one: LGBT movements? Disability movements? Both? Is bringing youth into this tangle of identities unhelpfully complicating things or a reflection of the complexity of life? Is looking at intersections helpful in creating allies and working generally towards a less oppressive society? Or stifling to any number of separate identity movements? Butler argues:

“If the term “queer” is to be a site of collective contestation, the point of departure for a set of historical reflections and futural imaginings, it will have to remain that which is, in the present, never fully owned, but always and only redeployed, twisted, queered from a prior usage and in the direction of urgent and expanding political purposes, and perhaps also yielded in favour of terms that do that political work more effectively”

(Butler, 1993a, 19)

Butler argues that if queer is about defying boundaries, queer theory itself must refuse to be boxed in. Imperative to queer theory is the discursiveness of the term, not queer theory, but queer theories (Hall, 2003). Furthermore, sexuality is about performativity; it is not necessarily that one is queer, but that one queers; making others think differently (Butler, 1993a). By asking 'is youth queer?', I reach out to queer theory to help me

consider youth productively within the lifecycle. Youth is often thought of as an awkward between-time, uncomfortably wedged between child and adult, young people portrayed as risky and rebellious (Youth as Active) or lazy and unproductive (Youth as Passive). Research question one asks: what dangers do young disabled people face if normative discourse remains unquestioned? Over the previous chapters, we have begun to see potential dangers of portrayals of youth to disabled youth. Young people are portrayed as incomplete-adults, a notion it becomes tempting to reject when we consider the normative ableism surrounding adulthood. However, rather than reject the ‘becoming’ status of youth, I propose in this chapter that it could be more productive to play upon this; considering youth not, as it is often portrayed, as a time of deficiency and lacking that precedes adulthood, but as a productive period within the continual becoming of life. Queer’s rejection of dichotomy and normativity means queering is “an exercise in thinking otherwise” (Shildrick, 2009, 168). I propose that disabled youth can help us in this politicising, queering, crippling, exercise of thinking-otherwise. Furthermore, as feminists, queer activists and queer theorists have argued, sexuality is “not a potentially pleasurable bonus enjoyed by a pre-established subject” but “an uncertain process that infuses all aspects of the materiality of living in the world [...] a core element of [...] self-becoming” (Shildrick, 2009, 126). Therefore, if I am to consider youth as a productive time of becoming, it seems essential to include sexuality in this discourse. Queer theory allows me to do this whilst forcing me to question normative/non-normative positionings of sexuality. A focus on disability, traditionally equated with asexuality (Garland-Thomson, 2002), makes this consideration even more imperative (considered further in *Chapter Eight*).

‘Kids are kids’: Postcolonial theory, disability and developmental discourse

To avoid perpetuating ableist and adultist stereotypes, disability is a vital component in any theorising of youth. Research question one asks what dangers young disabled people face if normative discourse remains unquestioned. I continue to address this question over *Section Two*, as we see potential dangers young disabled people face if normative discourses of youth are left unquestioned. However, I propose that by taking seriously disabled youth’s negotiations of adultist and ableist worlds, we can begin to think otherwise about youth and disability; thus, challenging normative discourse. As outlined above, queer theory allows me to consider sexuality within discourses of youth in ways

that avoid perpetuating normative stereotypes of sexuality and gender. Of equal use, however, is queer's "practice and ambition that unsettles, disturbs and challenges normative ways of living" (Goodley, 2011, 34). Normative ideas surrounding age and development are deeply engrained into society (Burman, 2008a). As I utilise theory in analysis over *Section Two*, we see the importance of theories challenging normativity for my research.

The extent to which discourses of age are naturalised within my own thinking became apparent when I was in discussion with another doctoral student towards the beginning of my research. She was doing research into the provision for children with autism in schools, and seemed to be taking a fairly 'social model' approach; the problem was the school not accommodating the child, not something located within the child. This led me to question why she was focusing particularly on autism, rather than taking a non-impairment specific stance, looking generally at the in/exclusion of disabled children in school. She spoke about the specific needs of children with autism. In an attempt to 'problematise' impairment categories (but with the more likely effect of 'normalising' them), I found myself protesting with the expression "but kids are kids". It is a phrase I have used similarly before, and heard used by other feminist/CDS/activist-y types. To this day, I have never been challenged for it. If, however, I was to say, "but, at the end of the day, gays are just gays", "Asians are just Asians" or "women are just women", the response would not be favourable (or, more accurately, it would not go unnoticed, and rightly so). Why is it that I do not question sweeping statements surrounding childhood, yet would jump to contest assumptions about other constituted populations? As Nodelman (1992, 33) highlights, "even those adults who happen to be feminists tend to talk and think of children of both sexes in terms of metaphors redolent of traditional assumptions about feminine weakness and passivity". If developmental psychology is one of the "last bastions of modernism in psychology" (Burman, 2008b, 47), childhood is a grand narrative that remains distinctly unquestioned; the implicit Other to the adult self.

Self/Other thinking led me to postcolonial theory. Colonialism is the process of subordinating another group of people in order to perform a takeover. The coloniser rationalises a takeover by constituting the colonised group as Other, distinct from itself. Constituting the group as Other justifies colonisation as a process of reform: civilising the uncivilised, making them like us. Postcolonial theory aims to contest this relationship; disrupting self/Other relations by challenging discourses emerging from

colonialism. Despite possible connotations of preceding the term 'colonialism' with 'post', postcolonialism does not mark colonialism as a historical phenomenon. Rather, it is a way of theoretically challenging colonial power and its legacies (Sherry, 2007). Young (2003, 74) writes that postcolonialism "offers challenge rather than solution [...] and allows its audiences themselves to interpret its new spaces with relevant meanings of their own". Research question two asks: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient? Postcolonial theory could be useful in thinking about and challenging normative developmental discourse, and therefore repositioning disabled youth. I therefore now introduce postcolonial theories that have caught my attention, before explaining how they help me rethink youth and disability.

My first tiptoe into postcolonial theory was at a seminar introducing the work of Bhabha. Bhabha's theories were introduced as one postcolonial attempt to challenge the continuing occidental view of the "irrational, unreasoned, propertyless, uncivilised class of people" which are required to maintain the ideal vision of "the rational, reasonable, civilised" Western European or North American individual (Goodley, 2011, 38). The seminar had nothing to do with age, developmentalism, youth, or disability, but got me thinking: irrational? Unreasoned? Uncivilised? Thinking back to *Chapter One*, this sounds like rhetoric surrounding Youth as Active. I came to Bhabha's concepts of mimicry (1984) and hybridity (1994). Bhabha draws on Foucault's theories of power-knowledge to argue that a colonial identity is not simply imposed by a coloniser, but arises from the complex relationships between coloniser and colonised (Childs & Williams, 1997). In order to remain dominant, the dominant agent attempts to stagnate power-knowledge relationships. The coloniser wants to 'fix' the colonised, keep them known and predictable; an unchanging stereotype of an ignorant, uncivilised and uneducated Other (Childs & Williams, 1997). Once the colonised peoples are constructed as 'lesser beings', the coloniser justifies entering a nation under the pretence of reform, justifying takeover on the moral grounds of cultivating, refining and enlightening the Other population by teaching them the ways of the self (Young, 2003).

For me, Bhabha's theories resonated with the positioning of disabled youth. We know (and will witness over *Section Two*), that disabled youth are not Youth as Passive. In *Chapter One*, I argued that Youth as Passive portrays young people in a pre-social state; given the right conditions they can be shaped to become 'suitable adult-citizens' (Wyn &

White, 1997). As we saw in *Chapter Two*, however, although this leaves society with a certain degree of responsibility towards disabled youth, this construct also leads to the less paternalistic and more demonising depiction of lazy, ignorant and apathetic young people. If we employ Bhabha's theories, we see the coloniser, in this case, those advocating normative adulthood (such as our friend, Mr Reasonable), attempts to stagnate a discourse of disabled Youth as Passive in order to maintain the vision of their normatively embodied, adult selves. Bhabha reasons, however, that justification of reform is a façade. To remain as the dominant agent current power-knowledge relationships must remain inline; the colonised must remain the static, knowable Other. A 'successful civilising process' of making 'them like us', would realign power-knowledge relationships, closing the gap between coloniser and colonised. Colonisers therefore "desire [...] a reformed, recognizable Other, *as a subject of a difference that is almost the same, but not quite*"; (Bhabha, 1984, 85), a concept Bhabha calls 'mimicry'.

Bhabha uses British missionary efforts in India to exemplify mimicry. Although entering India under the pretence of introducing Christian morals, for the 'good of the Indian people', only a *partial* diffusion of these morals was safe for the British colonial mission. If a complete reform took place the self and Other would no longer be distinct, there would be no Other by which to define the self, and no longer a justification for colonisation. A partial reform, however, results in mimicry of Christian values, whilst still ensuring a safe distance remains between the self and Other. In other words, although there is a façade of reform, civilising the uncivilised, making them like us, the coloniser must ensure a gap remains between the two parties: to ensure the self is upheld, the Other must remain distinct. Furthermore, whilst the colonised fails to meet colonial ideals, there remains legitimacy (in the colonisers' eyes) to repeated colonisation, discipline and reform – the Other still needs to be civilised.

We saw in *Chapter Two* that disabled youth are considered outside normative discourse of youth as becoming-adult. Considered 'at risk' of not conforming to adulthood normativity, they are subject to intervention which aims to carve them into suitable adult citizens (Kelly, 2006). Colonisation, however, depends on its own strategic failure. I argued in *Chapter Two* that normative adulthood benefits those already in power, at the expense of those excluded from it. To stabilise and justify the existence of a normative adulthood, young and disabled people are scapegoated as burdensome; support and assistance which would enable them to become the independent, economically

productive citizen of normative adulthood removed. For them to embody normative adulthood would threaten those already in power. For ableist adulthood to retain its pedestalled position, the gap between self/Other, disabled youth/non-disabled adult, must remain distinct. The attempt is to root disabled youth in a discourse of passivity. I argue through research question two (how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient?), that the construct of disabled Youth as Passive must be challenged. We see over *Chapters Seven* and *Eight* disabled youth doing just this through, what I conceptualise as, a mimicry (and mockery) of adulthood. I outline this further below.

Children's literature and the colonisation of childhood

Wondering whether others had linked theories of postcolonialism with developmentalism I came across a paper opening with the following statement:

“Child psychology and children's literature can be discussed and analyzed as the corporate institution for dealing with childhood – dealing with it by making statements about it, authorizing views of it, describing it, by teaching it, settling it, ruling over it; in short, child psychology and children's literature as an adult style for dominating, restructuring and having authority over childhood”

(Nodelman, 1992, 29)

Nodelman reassures readers that these are not his words but words he borrows from postcolonial theorist Said (1978) and inserted terms relating to childhood institutions. Nodelman (1992) argues that discourses of childhood and adulthood stand in binary opposition to one-another (Burman, 2008b). Adults confirm the difference of children to themselves through studying, speaking for, and gazing upon them, therefore exercising a controlling system of power-knowledge by creating a discourse of 'childhood' (Nodelman, 1992). These arguments resonate with Bhabha's concept of 'fixity': creating the stable 'stereotypical' subject. Children are therefore construed, paradoxically, as both “wonderfully innocent and woefully ignorant” (Nodelman, 1992, 34). Nodelman continues by making parallels between colonial and adult power, drawing on Rose's (1984) critique of *Peter Pan*. Rose (1984) argues similarly, writing of the presumed 'naturalness' of children, which on the one hand results in a nostalgic discourse of creativity and lost truths, but on the other constitutes a population of uncivilised, lesser-evolved and irrational children. We see links with disability: similar assumptions made

of disabled people, contributing to infantilising discourse (Johnson, Walmsley, & Wolfe, 2010). The presumed ‘naturalness’ of childhood and disability are used to juxtapose visions of virtuous, rational ableist adulthood (all terms that can be recognised in relation to colonial discourse: the colonisers gaze upon the colonised). By making childhood wonderful, argues Nodelman (1992), we make children not-quite-human. A discourse of less-than-human applied to disability with devastating consequences (Wolfensberger, 1969) (investigated further in relation to disabled youth in *Chapters Seven and Eight*). By portraying other cultures, nations and people as ‘less civilised’, colonisers legitimise their colonisation.

Rose (1984) and Nodelman (1992) use children’s literature to further their arguments. Rose (1984, 137) states that in her critique of *Peter Pan* she is not asking “what children want, or need, from literature” but “what it is that adults, through literature, want or demand of the child”. In a more general analysis of children’s literature, Nodelman (1992) argues similarly: we assume and want children to possess characteristics we feel are intrinsic to childhood, therefore, we give them books to bolster these qualities. We assume children to be creative so we give them books to teach them to be creative. However, whilst we want children to remain the Other (i.e. children) and represent everything we expect children to be, we also want them to be less childlike and more adultlike (the moral ending to the children’s story). We find children paradoxically attractive and dangerous:

“What we choose to understand as childlike irrationality or lawlessness or carelessness is attractively lax, a temptation to be less responsible, less mature, less adult. If adults have a secret desire to act childishly, and if that dangerous desire is engendered by the childish actions of children, then we must protect ourselves and our world by making children less childish”

(Nodelman, 1992, 31)

Children’s books therefore teach them to be both ‘childlike’, but at the same time ‘adultlike’ (Nodelman, 1992; Rose, 1984). Books for children try to capture the ‘wonder’ of childhood, whilst enforcing adult morals; to be less irrational, less egocentric, more ‘grownup’. Like the coloniser, adults want children to stay firmly fixed as children, yet paradoxically, also act more like them, more like adults. As Childs and Williams (1997, 132) put it in relation to Bhabha’s work: “the stereotype functions as a fetish”; the adult

simultaneously recognises herself in the child, yet disavows it. The child as almost adult, but not quite.

If all children exist under the colonial gaze of adults (and the Panoptic gaze of other children), then for disabled children, levels of surveillance are heightened. Ableist adulthood discourse means disabled children need keeping a closer eye on; they require more ‘work’ in order to ensure their conformity. Goodley and Runswick-Cole (2010) write that play for disabled children has become “a mechanism for assessment, diagnosis and therapeutic intervention” (500), first used to make normal/abnormal judgements, and then as an attempt to correct those falling into the latter category. “Disabled children’s play”, they argue, “has been colonised by adults seeking to support their learning and development at the expense of its intrinsic value”. Although to professionally judge certain forms of play as gender in/appropriate is perhaps now frowned upon as out of date (at least in a publicly overt sense), discourses about what is ‘age-appropriate’ remain strong (Burman, 2008a). Dis/abled children, playing in ways that do not ‘fit’ with their age (or, just generally, do not ‘fit’ with what children’s play ‘should’ constitute), are considered abnormal. Nodelman’s (1992) and Rose’s (1984) critiques of literature, and Goodley and Runswick-Cole’s (2010) interrogation of ‘play’ both point to similar conclusions; adults create discourses around phenomena and processes that frame them as intrinsically ‘childlike’, these processes can then be used to survey, judge and place demands upon children, with the aim of guiding them to normative adulthood. As Nodelman argues, and Bhabha’s theory of mimicry helps us to theorise, there is an adult desire to ensure that children remain distinctly separate, as children, yet, paradoxically, become less childlike and more adultlike; to remain as child yet mimic the adult. The child that is like adult, *but not quite*. As Nodelman (1992, 33) highlights, however, “what distinguishes our thinking about childhood from other discourses about otherness is that in this case, the other does quite literally turn into ourselves”, therefore:

“The irony... is as obvious as it is depressing: if our thinking about children is an act of colonization, then it is in fact ourselves we are colonizing, ourselves we are oppressing – albeit at one remove.”

(Nodelman, 1992, 33)

Ironic it may be, but depressing? Not necessarily. Re-enter youth. Re-enter disability. Re-enter queer.

Youth and mimicry

Developmental discourse teaches us that youth bridges childhood and adulthood. My arguments above link particularly with the concept of Youth as Passive: youth as a time to carve children, who will be passive in the process, into suitable ‘adult’ citizens (Kelly, 2006). In *Chapter Two* I began to address research question one by exploring dangers young disabled people face if a normative discourse of disabled Youth as Passive remain unquestioned. Yet, I also argued, and will continue to argue throughout, that discourses of Youth as Passive do not represent the lived-realities of young people’s lives. Rather, they are used at particular times, in particular ways, to do particular jobs. Today, notions of passivity are used to justify the destruction of the welfare state. Yet youth is not static. Discourses of youth are messy and contradictory. Youth as Passive is only one construct of youth. The anxiety aroused by active young people demonstrates young people’s ability to resist and define the categorisation that they are expected to slot into, as they inhabit a space between child and adult. The next chapter marks the beginning of *Section Two* where, through an analysis of the stories offered to me by young disabled people, I address research questions three and four: asking what disability and the lived-experiences of young disabled people can teach us about youth, and what youth and the lived-experiences of young disabled people can teach us about disability. I explain now how Bhabha’s (1984) concepts of mimicry and mockery will help me.

Discourses of colonised populations result from relations between coloniser and colonised (Bhabha, 1984). Therefore the colonised does not remain the static, knowable Other that the coloniser desires. With mimicry, Bhabha tells us, comes the danger of mockery. As the colonised subject realises her own inauthenticity within the colonial discourse she is able to pose as a caricature of the colonised. Bhabha calls this the ‘menace of mimicry’ (Childs & Williams, 1997):

“The ambivalence of colonial authority repeatedly turns from mimicry – a difference that is almost nothing but not quite – to menace – a difference that is almost total but not quite”

(Bhabha, 1984, 91)

Once the difference is noted, the colonised can pose as a parody of the coloniser. To the coloniser, this is a menace. There is a fine line between being like-us-but-not-quite and being too-like-us:

“With mimicry the authoritative discourse become displaced as the colonizer sees traces of himself in the colonized: as sameness slides into otherness”

(Childs & Williams, 1997, 130, original italics)

In ‘*Black Skin, White Masks*’, Fanon (1986) lists two alternatives available to the colonised person under colonial rule: ‘turn white or disappear’. Bhabha adds ‘camouflage’ as a third option: “the effect of mimicry is not to change [to turn ‘white’] but to camouflage” (Childs & Williams, 1997, 133) – to pose as ‘white’ in order to ‘fit in’. I would like here to pause a minute to think about the content of *Chapter One* where I voiced how on beginning my PhD I felt the need to ‘play grownup’. This was all done in a fairly tongue-in-cheek manner. Yet my attempts to ‘play grownup’ could be theorised as a mockery of adulthood. I recognised my difference from ‘adults’, worked out what constituted this difference, and proposed that I could trick adults around me into thinking I was one of them. I.e. adopt an adulthood camouflage in order to fit into an adult world. It is a strategy, I argue in *Chapters Seven and Eight* that young disabled people employ in order to fit into a discourse of youth as becoming-adult/woman. “In Foucault’s terms, Bhabha speaks of ‘the process by which the look of surveillance returns as the displacing gaze of the disciplined, where the observer becomes the observed’” (Childs & Williams, 1997, 131). Through my ‘theorisation of adulthood’ I was turning the gaze back from one on youth/childhood, to a surveillance of adults from the position of youth. At the end of *Chapter One*, however, I worried that, despite the joking, it would be all too easy for this role-play to become necessary and every day in order to survive in an ableist and adultist world. Worries I have in terms of the psycho-emotional wellbeing of my young disabled participants in *Chapters Seven and Eight*.

Furthermore, in my own deceptive (camouflaging? menacing?) mission I found that the ableist and normative rhetoric of adulthood means for disabled young people adopting adulthood camouflage may be harder than it is for me. Childs and Williams (1997, 129) write that for Bhabha, as well as a technique of colonial power, mimicry is “also a strategy of [colonial] exclusion through inclusion that purports to accept the ‘good native’ all the better to exclude and denounce the majority ‘bad natives’”. To pass as adult I assume the role of ‘good native’. Arguably for me to take this position is at the expense of others, such as disabled youth, who do not have the option of conforming. The language of ‘good/bad native’ is used within neoliberal rhetoric. In order for the ‘correct’ answers to be received, tokenistic consultation takes place with only the most ‘adult’ young people. This can then be used to legitimise service cuts as ‘what the people

want' (Fuller & Loogma, 2009). We are further bombarded with individualistic, neoliberal 'overcoming', 'if I can do it, anybody can do it', 'achieving despite of' rhetoric. These are good active youth. The result: an excuse to dismiss any form of youth activity that does not fall into the 'correct adult channels' as irresponsible and dangerous (discussed in *Chapter Two*). The dangers of mimicry warn me to be careful when faced with the desire to 'play grownup'. I argue in *Chapter Seven*, that there may be strategic times when disabled youth need to mimic ableist adulthood, for the purpose of survival. Yet such deception comes at the expense of other things. Therefore, I maintain the need for readdressing of youth and theorising adulthood, and the vitality of adopting a 'critically young' position which challenges adulthood normativity. I also argue in *Chapters Seven and Eight*, however, that disabled youth's mimicry of adulthood, can make a mockery of adulthood. This helps me rethink both youth and adulthood.

When discussing *Chapter One* I have continually received the same response: "I think we're all just playing grownup – I don't feel like an adult!" I have already asserted the impossibility of meeting up to the 'adult ideal' and I reassert it now: those appearing most grownup (our Mr Reasonable) are merely those sporting the best camouflage. Here I want to introduce Bhabha's concept of hybridity. In a later essay, *The Location of Culture*, Bhabha (1994) theorises the tension felt by colonisers as cultures meet and as coloniser and colonised become less distinct from one-another: a concept he terms 'hybridity'. He again uses the example of English missionaries, this time their distribution of the bible. Whilst the English sat at home waiting for the civilising work of the bible to take effect, its use had become hybrid: used as fuel and traded as a commodity (Young, 2003). Hybridity "works in different ways at the same time, according to the cultural, economic, and political demands of specific situations" (Young, 1997, 79). I am reminded of an appropriation of the bible in my own household. As a nine-year-old I was sent home from school with a bible and confidently told my atheist Dad that I was going to put it in the bin. Expecting praise, I was surprised when he instead asked if he could have it. Seeking further explanation, I was informed that bibles make brilliant doorstops. Bhabha argues that colonialism relies on "rules of recognition" and the belief in a "natural authority" that cannot be "allowed to be 'distorted' or 'disturbed'" (Childs & Williams, 1997, 134). It relies upon right/wrong, true/false, self/Other distinctions. However, as cultures meet hybrid forms "[break] down the symmetry and duality of the self/other" (Bhabha, 1994, 116), leading to questions of what constitutes the original, untarnished, unhybridised form. In a quest to Anglicise, it

must be clear what it means to be English, and what are imitations. Hybrid forms prevent clear duality; which came first, the bible or the doorstep? Returning to youth, with its hotchpotch definitions and contradictory discourses, I ask whether it could be reframed, not as a developmental post-child/pre-adult period that ends at adulthood, but a hybrid that disturbs child/adult binaries and that even the most ‘grownup’ of us embody if we allow ourselves to be ‘critically young’. Although I see danger in mimicry and mockery of accepting normativity, with hybridity, I see space for resistance.

Binary breakers: Hybridity, youth, disability and Deleuze

Youth unnerves us. Although passive youth are condemned as lazy and ignorant, a threat to the self-mediating entrepreneur, active youth are even more risky: excessive, unstable and disruptive. We are told young people are dangerous. Kelly (2006) argues that those labelled as ‘youth at risk’ (the riskiest of the lot!), including disabled youth, are those refusing to be the self-mediating, normative adult (*Figure 1, p.40*). Although I do not dispute Kelly’s (2006) point, I would go further, arguing that the very concept of ‘youth’ disrupts the binaries craved in order to promote structure and order. Youth therefore threaten neoliberal subjectivity. As Bhabha (1984) makes clear, imperative to successful colonisation is the gap between coloniser and colonised being kept open. Ensuring this difference remains, keeps coloniser and colonised as distinct and separate groups:

“... the discourse of mimicry is constructed around an ambivalence; in order to be effective, mimicry must continually produce its slippage, its excess, its difference”

(Bhabha, 1984, 85)

The argument that childhood is to adulthood as colonised is to coloniser, has a fundamental flaw, as youth *does* transgress this space; youth plays within the opening that the coloniser must work so hard to keep empty. Youth refuses to comply to the “desire for a reformed, recognizable Other, *as a subject of a difference that is almost the same, but not quite*” (Bhabha, 1984, 85, original italics). Therefore, youth offers potential for resistance. Youth as Active is the disruptive hybrid of childhood and adulthood; the clashing of childhood and adulthood; the distorting of childhood and adulthood. Youth threatens normative adulthood. As argued in *Chapter Two*, disabled youth (and disabled people generally) are routinely and dangerously positioned as passive. Yet, disability discursively sits alongside the construct of Youth as Active: it too is considered

disruptive, messy and unnerving. The prioritised neoliberal subject must be contained, autonomous and independent. Disabled people remind us of the instability of ‘the self’, “[provoking] anxiety, not because of their difference as such, but because they are too much like everyone else; worse yet, anyone could become one of ‘them.’” (Shildrick, 2009, 54). Whereas youth’s straddling of child and adult confuses us, leaving us unsure how to treat young people, by demanding intercorporeality (something we all rely upon, though endeavour to hide), the disabled body laughs in the face of distinction and definition, reminding us of the instability of the able body, and our own failure to embody the sovereign self (Shildrick, 2009).

Research questions three and four ask what disability and the lived-experiences of young disabled people can teach us about youth, and what youth and the lived-experiences of young disabled people can teach us about disability. Disabled youth, I argue, embody a productive place from which to challenge ableist and adultist normativity, thus helping me to address these questions. Over *Section Two* I draw upon CDS utilisations of Deleuzoguattarian concepts (see, for example, Gibson, 2006; Gibson, Carnevale, & King, 2012; Goodley, 2007a, 2007b; Slater, 2012a) in order to help me rethink and challenge neoliberal individualistic discourse which stabilise self/Other relations – whether these be disabled/non-disabled or youth/adult. Refusing the concept of the complete and sovereign self, Deleuze and Guattari (1972) ask us to reconceptualise a world thought to be made up of atomised units, to one based upon networks of ‘productive desire’. The ‘self’ is in flux, transitory, in a constant state of becoming, and it merges and moves between other ‘selves’. These networks make up ‘desiring machines’ or ‘bodies without organs’ (BwO). Gibson (2006) offers three examples of BwO: man-dog (a blind man and his guide dog); man-machine (disabled men and ventilators); and woman-woman-man (an attendant assisting her disabled employer to have sex with another person). Yet ‘desiring machines’ can and do extend beyond this, ranging from “a body or even a subject” to “an institution or even the universe” (Gibson, 2006, 190). These philosophies discredit any possibility of ‘lack’: as there is no ‘whole’ to be had, one cannot be lacking. For my project, this not only removes disability from discourses of ‘lack’, but also means neither can youth be considered ‘lacking’ ‘incomplete-adults’. Adulthood cannot be an end-goal of youth, and disabled young people cannot ‘fail’ in meeting signifiers of adulthood. None of us can claim to embody ‘whole’, ‘complete’, ‘sovereign’ adulthood. We are all ‘becoming’, yet we cannot ‘become-adult’ once the full-stop of adulthood is removed. Rather, we are *all* the hybrid of child and adult. By being vigilant to and

celebrating our differences from adulthood normativity, therefore, we all have the potential to be ‘critically young’: to consciously resist our sameness and reveal our different to adulthood normativity. As hybrid forms, we cannot totally separate ourselves from youth or disability. They shake the vision of the stable self, disturbing what we have convinced ourselves is ‘natural order’. I propose, therefore, that youth and disability make real and young and disabled people embody the ambivalence, the slippage, the excess, the hybridity, that Bhabha (1984) talks of. They both refuse the self/Other relation. They will not, as Derrida (1995) puts it, be domesticated.

Discussion

With the voices of CDS sceptics in mind, along with the warnings of Davis (2002) and Sherry (2007) of not oversimplifying and/or over generalising when doing intersectional work, I feel my task as a CDS researcher is to ensure that any destabilisation of norms, any deconstruction of naturalised categories, results in productiveness and positivity, rather than any legitimisation for a loss of political rights. Over *Chapters One to Three* I have begun to address research question one: what dangers do young disabled people face if normative discourse remains unquestioned? This has alerted me to the importance of challenging normative discourse. Queer theory has played upon ‘inbetweenness’ to destabilise naturalised, binary categories, whilst celebrating difference from the status quo. Others have already argued the queer/crip-ness of disability (McRuer, 2006; Sherry, 2004; Shildrick, 2009). Writing this chapter gave me the chance to think through what I meant when asking, ‘is youth queer?’ Youth unnerves us, leading to constructions of young people as dangerous, risky and rebellious. I have argued that it is youth’s hybridity, its transgressing and disturbing of child/adult dichotomies, its inherent messiness and inbetweenness and our own difficulty in defining and categorising it, that evokes the anxiety that surrounds it. Arguments that have been made similarly by CDS scholars in an attempt to reposition disability (Shildrick, 2009). By posing the question of youth’s queerness, I wanted to find a way to appreciate and play upon these as *qualities*, rather than deficiencies, of youth. Perhaps it is more productive not to assert that youth is queer, but that youth queers: slipperly attending to that space between adult and child that self and other dichotomies strive to keep open. Thought alongside disability, therefore, youth can be a productive place to begin imagining otherwise. In *Chapter Five*, I outline how my own research with disabled young people helps me to answer research questions three and four: what can disability and the lived-experiences of young disabled

people teach us about youth? And what can youth and the lived-experiences of young disabled people teach us about disability?

Through *Chapter Four* I have mulled over various theories (CDS, queer, postcolonial and Deleuzoguattarian) alongside youth and disability. Research question two demands this kind of transdisciplinary engagement when it asks how disability researchers can share the stories of young disabled people in order to reposition them as active and politically resilient. The link between them all the theories I have tapped into is their ability to challenge individualistic thinking inherent to neoliberalism, and imperative to secure self/Other relations. Shildrick (2009, 149) writes that “thought together, queer theory, disability and Deleuze mobilise a productive positivity that overcomes normative binaries, breaks with stable identity, and celebrates the erotics of connection”. I propose the addition of ‘youth’ to Shildrick’s list. Disability, unstable and interconnected, has the potential to destabilise the categories we have chosen to separate human beings into (Davis, 2002; Shildrick, 2009). Furthermore, if we emancipate youth from adulthood, embracing the becoming, transient imagery that surrounds it, and think of it alongside disability, we set ourselves along the road of imagining otherwise. Taking a ‘critically young’ position to embrace the hybridity of youth and disability helps free us all from the camouflage of ‘playing grownup’. I propose, therefore, that rather than denying the lived realities of disabled people’s lives, intersectional work done with and through the embodied, lived-experiences of disabled youth, is productive place to begin decolonised, otherwise thinking. *Section Two*, utilises theorisations and arguments from the last four chapters. Before this, however, I now offer you an intermission as we readdress Mr Reasonable.

Intermission...

Dear Mr Reasonable,

Over these four chapters of *Section One* I have contextualised my reasons for thinking about youth and disability together. In the introductory chapter I argued that for my project it is important to, like others within CDS, resist defining disability; instead appreciating it as a slippery concept (Shildrick, 2009). *Chapter One* aimed to do similarly for youth what CDS researchers have done for disability. I highlighted some of the confusing and contradictory rhetoric that surrounds youth, and began to understand youth under the headings Youth as Passive, Youth for Sale and Youth as Active. This framework has, and will continue to allow me to assess the positioning of disabled youth within discourses of youth.

In *Chapter Two* I highlighted that disabled youth are routinely positioned within a discourse of Youth as Passive. I began in this chapter to address research question one: what dangers do young disabled people face if normative discourse remains unquestioned? We saw that in current neoliberal climates, to be construed as passive is dangerous; disabled youth risk disposability (Giroux, 2009). *Chapter Three* furthered thinking around research question one. It considered the gendered concept of Youth for Sale. I argued that Youth for Sale abstracts ‘youthfulness’ into a health and beauty thing we are all (women especially) encouraged to buy into. The abstraction process was particularly obvious when taking disabled youth into account (Hughes, et al., 2005). I argued that although young disabled people are excluded from youth as becoming-adult, neither do idealised discourses of youth leave space for human diversity. I continue to address research question one through the analysis of *Section Two*. *Chapter Seven* considers the lived-consequences of excluding young disabled people from a normative discourse of youth as becoming-independent-adult; and *Chapter Eight* thinks through the dangers of Youth for Sale for young disabled women.

By highlighting in *Chapter Two* the dangers of disabled youth’s positioning as passive, we saw the importance of research question two: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient? In order to address this question I continue through analysis to dip in and out of theories and methodologies in order to share the stories of my young disabled

participants. *Chapter Five* explores my transdisciplinary method/ology. *Chapter Six* draws on feminist critiques of youth subcultural studies to highlight young disabled people creating their own spaces within a service-based setting. *Chapters Seven* and *Eight*, on the other hand, engage with young disabled participants' identity political fights, as well as the inadvertent and academic activism they are involved in (Garland-Thomson, 2002). These stories demonstrate disabled youth's active political engagement.

In *Chapter Four* I theoretically justified why I feel it is productive to think about youth and disability alongside one-another. I argued that youth and disability inhabit liminal spaces from which normative discourse can be questioned. Research questions three and four take up this gauntlet, asking what disability and the lived-experiences of young disabled people teach us about youth, and what youth and the lived-experiences of young disabled people teach us about disability. As disability has acted as my guiding theoretical lens throughout *Section One*, research question three has been considered throughout. Disability has helped me to think-through conceptions of youth (and adulthood). In *Section Two*, however, I further consider research question three and four through the lived-experiences of my young disabled participants. *Chapter Six* asks what young disabled people's exclusion from youth culture (Priestley, 2003), teaches us about youth culture. *Chapter Seven* explores young disabled people's ideas around youth as becoming-adult, and what this teaches us about youth, adulthood, and disability. *Chapter Eight* asks similar questions; this time, however, considering what young disabled people can teach us about disability, Youth for Sale, and womanhood.

As you see, Mr Reasonable, your lessons are not over yet. Although we have considered what it oppressive about your reasonable world, we have not yet considered alternatives. Before we turn to these teachings, let me now introduce you to my young disabled participants in *Chapter Five*. I will write to you again in *Chapter Nine*.

Speak soon,

Jen xxx

Section Two: Analysis and Synthesis through the Lived-Experiences of Young Disabled People

Chapter Five

Method/ology

Introduction

The method/ology marks the beginning of *Section Two*. My auto/ethnographic writing to (un)learn (Kleinsasser, 2000; Spry, 2001) continues throughout this section. Yet, the focus shifts, as we move from plotting the landscape of youth and disability, to focus upon the actions, theorisations and ideas of young disabled participants. The purpose of this chapter is to set out the ethnographic project which forms my fieldwork, of which there are three contexts:

1. A 10-week art project (10 x two-hour sessions) for seven young people involved in Explore, a charity running visual arts workshops for people with the label of intellectual impairment.
2. Three workshops with 20 young people (with physical, sensory and intellectual impairments) involved in a disabled people's organisation's (DPO's) Youth Forum (YF). This resulted in an additional research relationship, outside of YF, with one member, Colin.
3. A three month ethnography with young disabled activists running an Independent Living Centre (ILC) in Reykjavik, Iceland.

I share with you why I refer to the former two contexts, time with Explore and YF, as *The Best Ever Future Worlds Project*, before detailing my fieldwork.

Futurology and the *Best-Ever Future Worlds Project*

I have periodically worried about the intersectionality of my writing. A year into my PhD and I had become used to seeing 'where has youth gone from the discussion?' scribbled on my work, when my supervisor hit me with the big one: 'is this about disability anymore?' At home within CDS, this suggestion was frightening. Airing my worries to a colleague, she posed that maybe I was writing a series of stories about Mr Straight/Mr Able/Mr Big Society/Mr Normal, through the lenses of 'youth' and 'disability'. This seemed appealing; I do, after all, address my thesis to Mr Reasonable. My thesis is about more than young disabled people. As reflected in my research questions I use 'youth' and

‘disability’ as tools to critique the oppressive forces of neoliberal normativity. I remind you of these research questions now:

1. What dangers do young disabled people face if normative discourse remains unquestioned?
2. How can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient?
3. What can disability and the lived-experiences of young disabled people teach us about youth?
4. What can youth and the lived-experiences of young disabled people teach us about disability?

The above occurred as my first PhD year was ending, and I was keen to begin empirical work. I envisioned a year hanging out with disabled youth. As a 23-year-old, spending time with my peers under the guise of ‘work’ was appealing! However, critical of the penetrating gaze on disabled youth, I was conscious of reifying this gaze. Nevertheless, I had no desire to spend a year hanging out with Mr Reasonable. Although it does not end with it, my thesis is about youth and disability, and young disabled people were the people with whom I wished to spend time.

Thankfully, I had a ‘eureka!’ moment at a conference in summer 2012. By chance, I attended a presentation introducing the academic discipline of ‘futurology’ (Facer, 2011a). Futurology has its origins in war strategy and continues to be used in the financial sector; concepts that sit uncomfortably with the politics of my thesis. However, Facer spoke of futurology’s use within education. I have argued from *Chapter One* onwards the dangers of viewing youth as incomplete-adults. ‘*What are you going to be when you grow-up?*’, often translating to mean, ‘*What job will you have? How will you become a productive member of neoliberal society?*’ Questions doused in ableist and normative connotations, and therefore often denied to disabled youth (explored in *Chapter Seven*). Educational futurologists make a similar critique. However, rather than dismissing talk of the future, they argue shifting from talk of individual futures, to encourage young people to think about societal and collective futures (Facer, 2011b; Hicks, 2002). As traced through the previous chapters, initially I saw only negative connotations of the continual future focus when thinking/talking about youth. However, as theoretically justified in *Chapter Four*, drawing on Deleuzoguattarian notions of becoming, I had begun to wonder whether the ‘inbetween’ status of youth could be played upon; the adulthood full stop of becoming-adult removed to consider how youth

become-in-the-world-together (Shildrick, 2009). This seemed to correspond to the arguments of Facer (2011b) and others. I theorise around the notion of ‘becoming’ as it relates to the lives of my young disabled participants in analysis which follows.

Suddenly, futurology seemed relevant and I began exploring how I could utilise it in my research. This resulted in *The Best-Ever Future Worlds Project*, a utopian time-travelling project with young disabled people. My plan: to ask young disabled people to travel forward in time to a world set up just the way they want it. This would have dual purpose. Okely (1975) tells us that ethnography should not just involve observation, but participation and an exchange of beliefs (Davis, 2000). Not wanting to just ‘hang around’ young disabled people, acting as another point of surveillance in their over-surveyed lives (Priestley, 2003), the creative methods employed in *The Best Ever Future Worlds Project* gave me the opportunity to offer something to participants; it meant we could together share ideas about how the world could be otherwise (Goltz, 2009). Secondly, as I continue to address throughout this chapter, the project aided me to answer my research questions. Research question one asks: what dangers do young disabled people face if we fail to question normative discourse, specifically in relation to youth and adulthood? Offering an alternative vision of the future cannot take place without a simultaneous critique of the present (Geoghegan, 1987; Gordon & Hollinger, 2002; Little, 2006; Sargisson, 2000). Engaging in utopian thinking, therefore, highlights the dangers of normativity. Research question two asks: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient? Utopias are inherently political (Sargisson, 2000). *The Best-Ever Future Worlds Project* therefore highlighted participant’s active political resilience. Research questions three and four are about otherwise thinking: what can disability and the lived-experiences of young disabled people teach us about youth, and what can youth and the lived-experiences of young disabled people teach us about disability? Would youth and disability be thought differently in our future world?

After approaching various groups (the process of which is outlined later), I ran the two strands of the project, with Explore and YF, in the north of England between October 2011 and February 2012. I explain later the particular methods employed. From *The Best-Ever Future Worlds Project* with YF grew an additional research relationship with a young disabled activist, Colin. Interviews with Colin happened outside of YF, and although they began by ‘talking utopias’, they developed into broader conversations

about youth and disability. The final research context, a three month ethnography with young disabled people running Reykjavik's ILC, was not strictly part of *The Best-Ever Future Worlds Project*. Sargisson (2000) argues, however, that those involved in political movements are already engaged in utopian thinking. Therefore, I was interested in how the young people involved in the Independent Living Movement (ILM) in Iceland thought the world could function otherwise. Rather than employ creative methods as in the UK, however, in Iceland I relied heavily upon my research diary as a means of both generating and analysing data (Richardson, 1998). Again, this process is outlined further below.

Like Hughes et al. (2012, 315-316), I have justified my intersectional and transdisciplinary approach to research: the “view [I] have taken is that any intellectual system or social theory is fair game when it comes to building a case for emancipation”. My method/ology is no different. An engagement in a variety of disciplines is vital to answer research question two: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient? Before detailing the methods, ethics and analysis of research, I first explain my methodological influences. Drawing upon research paradigms coming from CDS and the new sociology of childhood, I outline the relevance of feminist futurology to my research. I move to position my project as utopian, and justify my use of this term. Research is both a theoretical and practical endeavour (Biklen, 2004). I turn to outline how the critically young positionality theoretically built up over *Section One* influences research practice. From here I outline methods used in the three research contexts, before dealing with ethical issues, data and analysis. Finally, I outline how I will answer my research questions over *Chapters Six to Eight*.

Methodological influences: Futurology, CDS and the new sociology of childhood

As my explorations of futurology continued I discovered feminist futurology. Similarly to educational futurologists, feminist futurologists argue that the future has been colonised, by Hollywood, corporations and big business. Those outside of these institutions are only encouraged to perform future thinking in terms of how will individually fit into already established systems (Gunnarsson-Östling, 2011; Milojević, 2008). Arguments from *Chapter Two* resonate. Barber (2007, 36) argues that young

people are “permitted to choose from a menu of options offered by the world but not to alter or improve the menu or the world”. I argued in *Chapter Two* that some, such as disabled youth, are not even given this “paradoxical liberty” (Garland-Thomson, 2002, 24). The message delivered is: there is no place for you in this world. Asking young disabled people for their decolonising and enabling future ideas is an important pivoting point.

CDS and the new sociology of childhood both write about the colonisation of research (Shakespeare & Watson, 1999). Paradigm shifts in the disciplines have challenged disabled people’s/children’s exclusion from research, by separately repositioning both groups as social actors with experiences to share. There are examples which integrate both paradigms to include disabled children’s experiences (Goodley & Runswick-Cole, 2011a; Priestley, 2003; Shakespeare, 2006b; Shakespeare & Watson, 1999; Wickenden, 2010). During the 1980s disabled people in Britain, tired of being objectified through individualising research, drew on the social model of disability to devise what became known as emancipatory research. Since this time, dogmatic notions of what constitutes emancipatory research have meant it is a contested term (Barnes, 2002; Oliver, 1997). Nevertheless, disability researchers have maintained, to various degrees, that disability research should aim to include, be relevant to, and ultimately be “firmly on the side of disabled people” (Goodley & Moore, 2000, 826). Wickenden (2010) highlights that although paradigm shifts in disability research had more overtly political aims, the shift in childhood research took place over a similar period. The *UN Convention on the Rights of the Child* (United Nations, 1990) states that children have the right to be heard on issues affecting them, and this, alongside approaches from the new sociology of childhood, have led to the repositioning of children as social actors (Best, 2007; Christensen, 2004; James, 2007; Leonard, 2007; Shakespeare & Watson, 1999). Children, scholars argue, should be listened to as children, their here-and-now experiences valued, rather than considered incomplete-adults and consulted via adult gatekeepers (Burman, 2008b; Christensen, 2004; Shakespeare & Watson, 1999). These arguments resonate strongly with my thinking around youth and the way I approach research with young people.

Burman’s (2008b) work on development highlights an important link: whether relating to global systems or individual child-to-adult development, the assumption is linearity and progression. Whereas feminist futurologists question the assumption of progression in

terms of global futures (Milojević, 2008), those coming from the new sociology of childhood (Christensen, 2004; James, 2007) and critical developmental psychology (Burman, 2008a) pose similar critiques around human development: arguments I have made around youth. The positioning of children as incomplete-adults means researchers have positioned them as a) too vulnerable and b) lacking in the competence to generate ‘valid’, ‘reliable’ data (Morrow & Richards, 1996). For disabled people, particularly those labelled with intellectual impairments, similar assumptions around lack of competence have been made (Bogdan & Taylor, 1994; Goodley, 2001; Oliver, 1997; Williams, 2011). The integration of CDS into the new sociology of childhood to reposition disabled children as social actors is on-going (Goodley & Runswick-Cole, 2011a).

Children’s inability to speak the ‘truth’ is a recurring justification excluding them from research (Morrow & Richards, 1996). Similar arguments conceptualise young people as hormone driven and overly emotional (Biklen, 2004). The gendered connotations of emotion are considered subversive; young people’s ideas and political engagement disregarded as ‘irrational’ (Jaggar, 1989). Youth are politically unreasonable; methodologically unreliable; and unable to research rationally. I strongly dispute that children/young/disabled people are any more or less likely to tell the ‘truth’ than adults/non-disabled people. Moreover, ‘truth’ does not concern me. If reality is silence (Fuller & Loogma, 2009) and truth is dangerous (Gergen, 2008), I required a method/ology that put fantasy on loud speaker. Feminist futurology is a useful theoretical tool in asking young disabled people about their best-ever future worlds. As well as giving feminists the ground on which to trouble the ‘violence of now’ through critiquing current patriarchy, futurology offers performative potential; space to think about the way things could be. Like youth subcultural researchers whose work I engage with in *Chapter Six*, methods inspired by feminist futurology help recast disabled youth’s ideas, actions and emotions as political; the heart of research question two: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient?

This was summer 2011. Suddenly my reading list translated from academic to sci-fi texts to be drawn upon in research. Although there are links between futurist thinking and utopias, the two terms are not interchangeable: whereas utopian thinking is about ‘the ideal’, futurology considers possible, probable and preferable futures (Hicks, 2002). I

was less interested in what was possible, or probable, but keen to find out participant's preferable futures. Although drawing on futurist thinking, therefore, I cast my research as utopian, rather than futurist. According to Geoghegan:

“...a utopian impulse or mentality [...] is grounded in the human capacity, and need, for fantasy; the perpetual conscious and unconscious rearranging of reality and one's place in it. It is the attempt to create an environment in which one is truly at ease.”

(Geoghegan, 1987, 2)

Standing by Geoghegan's (1987) sentiment, young people's fantasies, emotions and desires became intrinsic to my research. A theme emerging in *Chapter Seven* is that young disabled people felt constrained by others low expectations of them, continually told things were not possible. Utopian fantasy allowed me to prioritise desire over any rational, logical, is it probable/possible thought; allowing disabled youth to step outside all that is reasonable, whilst engaging with research questions three and four: what can disability and the lived-experiences of young disabled people teach us about youth? What can youth and the lived-experiences of young disabled people teach us about disability? I now turn to further justify my use of the word 'utopia' – a word I use deliberately.

Justifying utopia as method

For More (1972), utopia paradoxically means a 'good place' that is 'no place'. For my purposes, a utopia is a dream or a vision of an ideal world; it does not exist (it is 'no place'), yet it is a place we can strive towards (a 'good place'). "Utopia is the expression of the desire for a better way of being or of living" (Levitas, 2005b, 5). Asking young disabled people for their utopian ideas serves dual purpose; asking for alternative future visions calls for social and political action. Furthermore, we cannot envision a 'better place' without simultaneously critiquing the present (Geoghegan, 1987; Gordon & Hollinger, 2002; Little, 2006; Sargisson, 2000).

Utopian ideals are often presented as fictional narratives, classic literary examples include More's (1972) *Utopia* and Plato's (1998) *Republic*. Some fall under broad ideological categories (Sargisson, 2000), such as Morris' (1994) socialist *News From Nowhere*, or feminist texts, such as Gilman's (1998) *Herland* and Piercy's (1979) *Woman on the Edge of Time*. In all the above examples, stories form around a native

whom guides and teaches a foreign visitor around the utopian land. This allows the visitor to question the utopia relatively to present day values, whilst the guide explains why the utopian world is preferable (Abbott, 2004; Sargisson, 2000). The guide/visitor format gives the author/reader space to question the present day status-quo. As detailed later, in *Explore* this idea inspired a ‘newsflash’ style of interviewing, where young people told me about their best-ever future worlds through role-play. Utopias are both a reflection of, and reflective about, timely dilemmas. Therefore, although fictional, utopias are politically engaged (Sargisson, 2000). Research question two asks: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient?

A utopian project helps me highlight the political thinking of those not explicitly politically engaged, such as those involved in *Explore* (*Chapter Six*). Furthermore, although perhaps most overtly used within the literary genre, utopian thinking is not confined to this usage (Sargisson, 2000). Sargisson (2000, 1) argues that ‘intentional communities’ (which she defines as “a group of individuals, organised for some purpose” – such as those living in what we may deem ‘alternative’ communes and communities, or indeed, young people I spent time with in Iceland) to be utopian projects. The ‘utopian impulse’ is present in architecture, medicine, music, religion, art and philosophy (Sargisson, 2000). For my project, utopian thinking aids us to imagine otherwise.

Utopianism, however, is not without its critics, who deem it to be “‘unrealistic’, ‘irrational’, ‘naïve’, ‘self-indulgent’, ‘unscientific’, ‘escapist’ and ‘elitist’” (Geoghegan, 1987, 1). ‘Utopian’ used to belittle an idea as ‘impossible’: political proposals deprecated as ‘grand utopian thinking’ (Geoghegan, 1987; Sargisson, 2000). Cameron, for example, dismissed the *European Union* for its “grand plans and utopian visions” (Cameron, 2011). Conversely, the leader of the UK’s *Green Party* (2011) described Cameron’s *Big Society* as a “dream of utopia hiding nightmare of devastating cuts”. Geoghegan (1987) highlights that demands for women’s suffrage and the welfare state were once dismissed as unrealistic utopian ideals. The same arguments are employed today: young people demanding free education (McSmith, et al., 2010) or disabled people demanding IL (discussed in *Chapter Seven*), deemed unreasonable. For me, utopian thinking challenging what is reasonable can only be a good thing. Yet, criticism of utopianism goes on:

“For the antiutopian, utopians (1) are preoccupied with ends and are indifferent to means; (2) view persons and society as totality; (3) make firm and dogmatic assumptions; (4) are obsessed with management; (5) neglect human variety”.

(Abbott, 2004, 44)

The tendency of utopian thinkers’ to “neglect human variety” (Abbott, 2004, 44) is pertinent to disability researchers. Abbott (2010, 874) points to eugenic practices in utopian texts when asking “should utopian’s have perfect bodies?”

“In More’s utopia, the very ill are reminded that they exist only as a terminal for “feeding germs”. Morris’ utopia is peopled only by attractive and healthy people perhaps as a result of an implicit eugenic policy.”

(Abbott, 2010, 875)

Although Abbott draws on feminist critiques of bodily perfection to trouble bodily ideals within utopian fiction, he fails to acknowledge affirmative theories of disability. The eugenic tendencies of some utopian fiction could deflect those doing disability research. I feel, however, it calls for further engagement.

Arguing traditional utopian thinking neglects the family, sexual relations and childrearing, feminists have demanded that ‘the personal is political’ in their utopian writing by offering feminist alternatives (Sargisson, 2000). In Piercy’s (1979) *Woman on the Edge of Time* traditional family roles are questioned: women no longer primary carers of children, but children looked after by three guardians with no biological relation. Research question four asks: what can youth and the lived-experiences of young disabled people teach us about disability? Incorporating disability into utopian visions challenges a discourse of passivity and tragedy.

Rules protecting traditional, institutional-bureaucratic utopian visions, critics argue, mean utopia soon slips into dystopia (Abbott, 2010). Although Levitas (2005a) argues that critics are confusing utopianism with the problem of totalitarianism, the finite nature of an institutional-bureaucratic utopian visions are nevertheless at odds with postmodernity’s (and my postconventionalist) dismissal of grand narratives (Chrysanthou, 2002; Sargisson, 2000). Sargisson (2000) argues, however, that we should move from patriarchal blueprint definitions of utopianism, instead calling for a ‘transgressive utopianism’. Transgressive utopianism, is not about “single answers and easy programmes of action” (Sargisson, 2000, 1), but is partial, fluid and slippery; a way

to appreciate the transformative potential of dreams and fantasy. Sargisson (2000, 1) believes this form of utopianism can help us to mull over questions such as: “What do we want? What do we believe to be wrong with the world? How can we best change it? How should we live? Given the world as it is, how can we best achieve our dreams and desires?” Questions disabled youth are denied.

“Utopias – good places that are no place – are [...] outside the real world, but engage critically with it. They arise from discontent and attempt creative imaginings of how things might be better. They provide for bodies-of-thought spaces in which creativity is possible, they add momentum and resist the petrification to which academic minds are vulnerable. They give to social and political movements a sense of direction or vision.”

(Sargisson, 2000, 3)

Section One formed as I theorised around my own discontent with the world. Yet, as I argued in *Chapter Four*, for me, it is possible to pose as adult; an option often unavailable for disabled youth. Transgressive utopian thinking is best done by those on the peripheries who are most able to offer a transgressive critique (Sargisson, 2000). Young disabled people fulfil this ‘Othered’ criterion. They are well positioned to offer us a critical view of the world. As Shildrick writes:

"In place of the demand for rights, choice, and self-determination that presently shape the dominant discourse of disability activism, a more open and productive model that celebrates the qualities of those already living at the margins might be proposed."

(Shildrick, 2004)

A utopian project lets us celebrate, listen to and learn from the ideas, actions and imaginations of disabled youth. Furthermore, by asking participants wide societal questions, rather than asking directly about themselves, I am not demanding access to their lives. The intention being that I go some way in avoiding reifying the penetrating gaze placed upon young and disabled people (Priestley, 2003). This is not to dismiss conversations around the individual; as discussed later in this chapter, *The Best-Ever Future Worlds Project* allowed for levels of analysis ranging from the subjective to the cultural. However, it allowed for an aspect of choice on participants part. They could talk to me about themselves, or about their wider societal, cultural and political ideas. Furthermore, the creative methods I employed allowed members of the groups I worked within to take part without any particular direct engagement with me, which some preferred. This was an access requirement, as much as ensuring buildings were

wheelchair accessible. I turn to consider how futurist/utopian ideas fit with the critically young methodology pointed towards in earlier chapters.

A critically young methodology

“The need to listen carefully, or to find a way to take seriously the words of youth depends not only on methodological issues but on theoretical ones as well”

(Biklen, 2004, 722)

Biklen’s assertion resonates with paradigm shifts outlined earlier in the new sociology of childhood and disability research (Priestley, 2003; Shakespeare & Watson, 1999; Wickenden, 2010). For new research approaches with formally silenced groups to emerge, a theoretical repositioning has to conceptualise them as social actors with ideas to share (Biklen, 2004). Being critically young is both theoretical and methodological.

Butler (1993b) distinguishes between being virtually queer, “which would be experienced by anyone who failed to perform heterosexuality without contradiction and incoherence (i.e., everyone)” (McRuer, 2006, 30), and critically queer, which would mean “working to the weakness in the norm”, using the inevitable failure to meet up to this ‘ideal’ as a way of mobilising. McRuer (2006, 30) draws on this to distinguish between being virtually disabled and, what he terms, “severely disabled”:

“Everyone is virtually disabled, both in the sense that able-bodied norms are “intrinsically impossible to embody” fully and in the sense that able-bodied status is always temporary [...]. What we might call a critically disabled position, however, would differ from such a virtually disabled position; it would call attention to the ways in which the disability rights movement and disability studies have resisted the demands of compulsory able-bodiedness and have demanded access to a newly imagined and newly configured public sphere where full participation is not contingent on an able body.”

(McRuer, 2006, 30)

Like McRuer (2006) argues in reference to disability, I argued in *Chapter Four* the impossibility of embodying adulthood. We are all some hybrid form of child and adult. We can all be critically young by being vigilant to and consciously working against adulthood normativity: using the inevitable failure to meet up to adulthood normativity as a way of mobilising. I have argued from *Chapter One* onwards that adulthood is an ableist and heteronormative concept. Being critically young therefore requires us to

simultaneously be critically queer and severely disabled. Being critically young through a utopian project opens up the possibility of “a newly imagined and newly configured public sphere where full participation is not contingent on an able body” (McRuer, 2006, 30) nor on the embodiment of adulthood ideals. Rather, we celebrate the non-conformists of youth and disability as they help me to consider research questions three and four: what can disability and the lived-experiences of young disabled people teach us about youth? And what can youth and the lived-experiences of young disabled people teach us about disability? I go one step further than those in the new sociology of childhood, therefore, not *only* approaching young disabled people as social actors with views to share, but arguing their marginal position is an advantage to ‘imagining otherwise’ (Shildrick, 2004).

The second part of my critically young methodology directly concerns the methods employed. Stepping outside of the ‘reality of the present’ and imagining one’s own utopia is hard. The arts and sci-fi therefore became useful resources. In a participatory project, Goltz (2009) used various methods (art, music, dance, writing) to ask young queer people “what does a queer future look like?” (566). Reflecting on the project, one participant responded “it was easy to write about the future at first. I put down marriage and kids, but then realized that wasn’t me. I’d never thought about it before” (571). Goltz writes that “fantasy was weighed down from the position of our current paths” (577), however, using a range of innovative methods the group was able “to escape the box of “now” and explore possibilities not presently conceivable” (577). Here again, we see crossover with disability and childhood research. Walmsley (2001, 189) argues that strives to make the whole research process accessible to people with intellectual impairments have led to creativity in the research process; and research involving children often adopts similarly creative methods (Best, 2007; Hay, Fawcett, & Bancroft, 2008). As a result data often consists of multiple strands (Darbyshire, MacDougall, & Schiller, 2005) and does not always appear in a traditional format, but may include written transcripts, alongside other medium such as photographs, artwork, video, and so on (see, for example, Wickenden, 2010).

Whether research with children warrants different methods to that with adults is debatable (Punch, 2002). To adopt different methods when working with formally silenced groups is to position them differently in relation to the powerful (pseudo)norm. Writing as youth work practitioners and academics, Jeffs and Smith (1999) problematise

the ‘youth’ in ‘youth work’. They argue that as ‘youth’ is itself a contested and weighted term, there are potential problems for those setting out to do youth work; not least arbitrary age boundaries and perceptions of who ‘needs’ youth work preventing many access to skilful practitioners. I argue similarly around research: creative methods, whether they are developed specifically for working with children/disabled/young people, can be helpful in a range of settings (Best, 2007; see Kellock et al., 2009, for creative research methods used with adults). Following Jeffs and Smith (1999), although I am at times critical that some services aimed at young people, attempt to fit them into normative adulthood (Kelly, 2003), I am not trying to insight any ‘us and them’, researcher/disabled people/practitioner binaries. Rather, I concur with Goodley and Clough (2004); researchers can learn to work innovatively with people from examples of good practice in other settings. Drawing on creative practice, therefore, becomes the second part of my critically young methodology. I embraced the subjective, partial and incomplete researcher/ed in journeys (to the future) together. I saw my researcher role being similar to that of Goltz, when he writes:

“As researcher, I embraced my role as cocreator with the participants. I performed in activities, engaged in discussion, danced, sang, and played. Typical to the ideals espoused by participant action research (Kemmis & McTaggart, 2005), the line of researcher is one I worked to challenge, blur, diminish. The research space was designed to be generative for each of us, and my personal research marked one of many investigations that occurred simultaneously and collaboratively within this group. The data consist of the relationship and experience of the participants, myself included because I am inextricably part of the research.”

(Goltz, 2009, 567)

I consider the analytical implication of my positionality towards the end of this chapter. For now though, I turn to further outline the recruitment and methods employed over the different research contexts.

Research contexts: Recruitment and methods

Explore

Since 1985 Explore has run art projects for adults, youth and children with labels of intellectual impairment. As a charity, Explore relies on various donors such as the local council, *Arts Council England*, and *National Lottery* for funding. The group I spent time with was aimed at young people between 10 and 18 and funded by the government initiative, *Aiming High for Disabled Children*. During my time with the group the seven

members ranged in age between 12 and 17. Explore usually runs twelve-week projects centred on a theme, which participants respond to using a variety of mediums: photography, ceramics, textiles, and so on. Unlike the other two research contexts Explore is run for rather than by disabled people. There are five art tutors with various areas of expertise who run the workshops. Additionally, there are three members of office staff and a transient and enthusiastic cohort of volunteers and students. The building is small and busy, with people coming and going; adult members often popping in during the youth workshop. It was a lively and fun place to spend time. Explore regularly exhibits work in high-profile public venues.

I first came across Explore when searching for disability arts-based organisations online. Although enthusiastic about the arts, I have no formal training and a lack of resources, so the equipment and expertise apparent in already established groups was beneficial. I therefore created a *PowerPoint* presentation (included on *DVD 1*) which would play on a single ‘click’ and explain with minimal text, also read by a voiceover, who I was and what the project was about. After emailing this to several arts organisations for disabled youth in the north of England, the coordinator of Explore, Jill (pseudonym), invited me in for a chat. She thought my *Best-Ever Future World* idea could work as one of Explore’s project themes, and asked if I would run a ten-week project (rather than the usual 12, due to the Christmas holidays), with the support of two art tutors. I had a follow-up meeting with the tutors in mid-September to plan the project. I spent two sessions as a volunteer to get to know the group before starting *The Best-Ever Future Worlds Project* in October 2011 (*Figure 9, p.130* illustrates dates of meetings and workshops in the British fieldwork contexts).

I created various ‘research tools’ to be used with Explore. These included ‘*Reports from the Future*’ (see *Appendix One*); booklets introducing the research and providing a place for participants to plan their ideas. They opened with the text:

“Welcome time traveller.

Your mission: You have travelled forward in time to a world that is just as you like it.

Here, everything is just as you wish.

It is your best-ever future world.

Please use this book to report back on what you find.”

(Introductory text from *Report from the Future* booklet used with Explore)

The booklets then asked young people questions about what they found in their best-ever future world, including: you have arrived in your best-ever future world, what do you see? You meet someone from your best-ever future world, what do they look like? Where does the future person live? Space was left for young people to draw, stick or write their answers. They were encouraged to approach the task in their preferred format.

Young people were first asked to draw their time-travelling avatar, create a name (which could be their own, or a fictional name) and choose an age (their own, or a different age) for their time-traveller. I asked those that chose to use a fictional name if they would like me to use this as their pseudonym in my work. One chose his own which was changed for purposes of anonymity. Explore members are as follows:

1. Dr Lelo
2. EJ1234
3. Gareth
4. Jeff
5. Pause
6. Princess Hanna
7. Sooboo

Not all young people attended all sessions; Princess Hanna and Dr Lelo were only present for the final two sessions; and Jeff only came for two towards the beginning of the project. The remaining four young people attended the majority of sessions. I further introduce young people as and where their ideas and artwork appear over the following analysis chapters (predominantly, *Chapter Six*).

All young people started with '*Reports from the Future*'. From here, the approach varied between young people. EJ1234 and Sooboo took only one week to fill in the report. Sooboo spent the second week creating a timetable of his day in the present, and contrasting this to his future world. EJ1234 had the same sheet to complete, but instead used his cartoon skills to make the sheet into a cartoon strip about his time travelling day (*Appendix Two*). Some young people were happy for me to sit and talk to them about their ideas as they worked, others, such as EJ1234 and Gareth, preferred to work alone. EJ1234's passion for animation meant he also enjoyed acting out the dialogue of his cartoon strips. EJ1234 therefore told me about his future world through the dialogue of his cartoons, and by us together recording 'newsflash' style interviews, in which I was an

interviewer and EJ1234 a time-traveling reporter. The excerpt below is from the beginning of our first newsflash interview:

Jenny Hello and welcome to Reports from the Future on the BBC. I'm here with time-traveller EJ1234. Can you tell us where have you been?

EJ1234: I've been to the future!

Jenny: And what did you find there?

EJ1234: Oh it was scary. There were DINOSAURS! But I also met the king!

(Newsflash interview with EJ1234: 17th October, Explore)

Other young people wanted to try this interview technique, enjoying the use of the Dictaphone, but EJ1234 was the only young person whose interviews were solely in this format. In retrospect, this seems similar to that of 'native' guide and 'naive' explorer present in both ethnographic literature (a classic example being Malinowski, 1922) and utopian fiction (such as, Piercy, 1979). Some of the young people in attendance less regularly were not interviewed due to time constraints. Gareth chose not to be interviewed, but was happy to complete the tasks.

Part of my attempt to balance power was to let young people make research decisions. I outline in the *Ethics and Disability Politics* section of this chapter that these were micro-level decisions around data collection, rather than what research questions were asked. Nevertheless, allowing young people to make micro-level decisions meant the approach taken with Explore evolved from envisioned group work, to the creation of individual art pieces. I entered with the rough plan that young people would spend two weeks working individually around their own utopian visions, during which time they would collectively decide on a group art piece to construct over the remainder of the project. As a researcher, I was interested in discussion generated when young peoples' individual utopias were brought together. However, the following conversation with Pause was recorded in my research diary after the second session:

Jenny: What do you think we should do for our group art piece then?

Pause: Group art piece?

Jenny: Yeah, after we've done these Reports from the Future we can do a bigger piece together, as a group.

Pause: No I don't think we should do that

Jenny: Why not?

Pause: Because what if my ideas don't fit with Justin's ideas?

Jenny: Maybe that's interesting? How our best-every-futures could fit together – maybe that's something we could think about?

Pause: No. I think we should do separate art work, I suppose if you wanted we could put them next to each other at the end.

(Research diary, 17th October, Session Two, Explore)

Talking to Pause, I realised that although I was there foremost as a researcher, the young people attended for different reasons. Other participants agreed with Pause and chose to develop their own separate art pieces. This allowed the young people the chance to express themselves in the way in which they felt most comfortable. Rather than expecting the young people to communicate with me through speech or text - signifiers of adulthood coherency (Erevelles, 2000), taking heed from creative approaches to research (see Goodley & Moore, 2000 for research with people with labels of intellectual impairment; Hay et al., 2008 for children; and Wickenden, 2010 with disabled youth), meant I could appreciate different ways of knowing and communicating, as well as allow space for autonomy, that disabled young people are routinely denied (Priestley, 2003).

After the first two weeks I attempted to allow young people to take their own direction. I brought young people written individual instructions, signed off by a nameless time-travelling guru. These thanked young people for their work so far, before suggesting possible directions for their work. This meant I could be flexible and work from individual's positions, rather than imposing a one-size-fits-all set of methods. From spending with young people and chatting to staff who knew them well, I decided that for some young people it would be useful to offer more concrete examples of what they could do next, whereas others may prefer a broader remit. All instructions directly addressed them as time travellers and noted particular examples from their '*Reports from the Future*' (see *Appendix Three*, for an example). The format also meant I could sit and talk through instructions with those who wanted, but let those who preferred not to speak with me work alone. Most importantly, it was a format the young people seemed to enjoy. It became a familiar scenario that young people would enter anticipating their next set of instructions.

From here, each participant created an individual art piece sparked by an idea in their booklet. For some, this reflected a particular aspect of their utopian vision, such as Pause's environmentally friendly *Rainbow World* (*Figure 4* overleaf and *Appendix Four* for more pictures). For others, it was a chance to try out a particular artistic technique;

Sooboo requested he used the project to “try something new”, deciding upon 3D to create his *Green Land with Warm Winds and a Dentist* (Figure 5 below and Appendix Five for more pictures), and EJ1234 was keen to further his interest in animation (DVD2). The finished individual pieces are all included on DVD1, except EJ1234’s animation which is included on DVD2. My time with Explore is drawn upon most strongly in Chapter Six.



Figure 4 Pause's environmentally friendly 'Rainbow World'



Figure 5 Sooboo's 'Green Land with Warm Winds and a Dentist'

Youth Forum (YF)

YF is a project run by two disabled youth workers who are members of, and employed by a DPO in northern England. Basing its philosophies on the social model separation of impairment and disability (Oliver, 1990), the DPO was established in 1985 and is run by and for disabled people. YF meetings last two hours, and take place every three weeks in the DPO’s building. According to its promotional documents:

“[YF] supports young disabled people to gain greater control of their lives and to make a smooth transition towards adulthood. The project:

1. A group of young disabled people meet and discuss issues such as expressing yourself. The meetings are an opportunity to meet new people, gain support from each other and have some fun.
2. We offer peer support and training on issues like independent living.
3. Young people are offered advocacy support to assist in removing barriers faced in accessing services (housing services, etc.)”

(The Aims of YF, according to promotional documents – wording altered to maintain anonymity)

There are 30 members of YF who are between 15 and 25 years-old and have various labels of intellectual, physical and sensory impairments. Members choose which sessions they attend. Some are involved in other projects within the DPO such as the ‘access audit team’ that assess the accessibility of local places, and peer mentoring. In all, workshops I ran were attended by 20 different young people, though not all young people came to every workshop.

Like with Explore, I approached YF by emailing my introductory *PowerPoint* presentation (*DVDI*), and received an invitation to meet the two youth workers running the project. We met in the DPO’s building in October 2012 (see timeline detailing UK fieldwork, *Figure 9, p.130*). At this meeting we discussed the methods I was using with Explore. The youth workers were keen that I used similarly creative methods with YF to promote group discussion. However, as the group was larger and there were neither artistic materials nor expertise on offer, the approach with YF inevitably varied. Nevertheless, the focus remained on talking about how the world could function otherwise. We decided that I would a number of workshops, as well as attend an additional YF meeting to introduce my research to the group (see *Figure 9, p.130*). I summarise the different workshops below, before extrapolating them in more detail:

Workshop/Meeting	Date	No young people	Others in attendance	Aim	Duration
Cameras Workshop	31/10/11	7	Two youth workers, two PAs	Young people to take pictures of things which annoy them around a city centre. Pictures to be returned at first futures workshop and used as a base to think about how the world could be different in the future.	3 hours
Introductory Meeting	2/11/11	17	Two youth workers, one PA	Introduce myself and the project to young people who were not at the cameras workshop.	½ hour
First Futures Workshop	23/11/11	20	Two youth workers, one PA	Bin/post-box activity: to think about things which annoy the young people in the here-and-now, before turning to think about how they would like these things to be different in a future world. Make best-ever future world posters.	2 hours
Second Futures Workshop	13/01/12	18	Two youth workers, one PA	Recap around discussions we had in November. Spend longer making the posters.	2 hours

Figure 6 Workshops with YF

Cameras Workshop

YF's busy schedule meant the cameras workshop was timetabled for a weekday, before I had chance to meet the group. Many young people were at work or college, and only seven were able to take part. On the day of the workshop I discussed my research and the aim of the session with the young people. As one member had a hearing impairment, I also gave young people an additional information sheet about the workshop (*Appendix Six*). I deliberately left the instructions for young people vague, not mentioning 'disability', as, in line with my intersectional approach to research, I did not want to assume 'disability' would be the main thing on young people's agendas. After running the cameras workshop, however, I left feeling frustrated; struggling to know how to balance my priorities as a researcher, with those of the youth workers running the group:

“I gave instructions to the group that we were going to take pictures of things that annoyed us. Young people seemed to ‘get it’. I handed the cameras out and they were just moving off to begin when Paul [youth worker] stopped them. “I think what Jenny means is that you need to take pictures of things that are inaccessible”. But I deliberately avoided the word ‘accessible’. I wanted young people to have freedom to take pictures of anything annoying them: dog shit on the road, rubbish weather. I wasn’t sure what to do, should I say something? On the spot, I let the comment go. Maybe the young people would have taken the same pictures, I’ll never know.”

(Research diary, 31st October 2011, after cameras workshop with YF)

Unlike with Explore earlier, where I felt altering my research plans was at the guidance of young people, with YF I worried my research was being guided by youth workers. Literature around research with children and young people notes potentially difficulties of negotiating with adult gatekeepers (Leonard, 2007). For me, however, my own positionality was also at play. Firstly, as a young woman within the age category of YF members, I sometimes felt paternalism towards me. We see it above as Paul attempts to help me explain the task. I was also conscious of my position as a non-disabled researcher doing disability research within a DPO. A later quote from my research diary:

“I’ve felt awkward on two occasions now as a non-disabled person within YF. The first time was when I met the youth workers. They seemed excited about my ideas and we were having a joke, when Margery [youth worker] became serious, turning to me, “now, I have to ask you this, are you disabled?” Declaring myself non-disabled, she patted my arm, consoling me: “that’s ok”, she said. Then today [first workshop with the YF] Margery added to the discussion, beginning with the phrase “we’re all disabled people”. I didn’t know whether I should declare my difference: “well, actually – I’m not!” I kept quiet and went with it. Would they consider me a more authentic researcher (or ally?) if I had declared myself disabled? I could have done – I’m sure no impairment questions would have been asked. Some members of the group invited me along to the Christmas ‘do’. I would have liked to go, but felt I had to decline - if I was a disabled person, I would be in the age bracket to be part of the YF, but it’s not a ‘space’ for me (even if young people wanted me there, I don’t think Margery and Paul would have approved).”

(Research diary, 23rd November 2011, after first futures workshop with YF)

The role of a non-disabled researcher doing disability research is contentious (discussed later in the chapter). I was conscious of not being viewed as a careerist non-disabled researcher, benefitting from disabled people’s oppression (Oliver, 1998; Priestley & Stone, 1996). I felt grateful to be allowed into the organisation. Although I do not consider my research to be ‘emancipatory’ (Barnes, 2002; Oliver, 1997), like Liddiard

(2012, 77), I wanted “to adopt the spirit and ethos of [an emancipatory] approach, and remain true to the identifiable central tenets of consultation, accessibility, empowerment and relevance”. These young people were coming together as a group of disabled people, perhaps I had to allow the social model focus of the DPO to, on occasion, lead the research. Yet the arguments of disabled women (addressed in *Chapter Three*) niggled (Crow, 2012; Morris, 1992). I wondered how comfortable YF members felt talking to me ‘outside disability’ within this organisation.

Goodley (2000), however, warns us against making snap judgements about an organisation, based upon preconceived ideas. I did not want to make presumptions about the organisation on the basis of this initial scenario and the cameras workshop. On the spot, I let the ‘accessibility’ comment go. Some of the young people were part of an ‘access audit’ team in which they assessed buildings for physical accessibility. Many of the photos at the end of the cameras workshop were focused on tangible notions of ‘accessibility’. I discuss this further in *Chapter Six*. I did, however, also get chance to chat to the young people during the session about less tangible things that annoyed them: the lack of disabled young people on TV was a recurring conversation, and some young people pointed to less ‘disability focused’ annoyances, such as the cost of a burger at the train station.

Introductory Meeting

To reincorporate the intersectional approach to fieldwork I used photos from the cameras workshop alongside ideas from the less ‘accessibility’ focused conversations, to design posters which I took to meet the rest of the group (*Figure 7*). As well as help me explain the project, I could refer to the posters if encountering similar scenarios to the cameras workshop. One participant at the cameras workshop, Colin, had requested to be more involved in the project. I therefore emailed Colin the posters before the workshop to see if he thought they were suitable. I was concerned about a) their accessibility and b) not wanting to patronise the group. On Colin’s approval, I took posters along to YF and left them for young people’s reference after the meeting. The introductory and subsequent meetings went well, with discussion moving beyond physical accessibility.

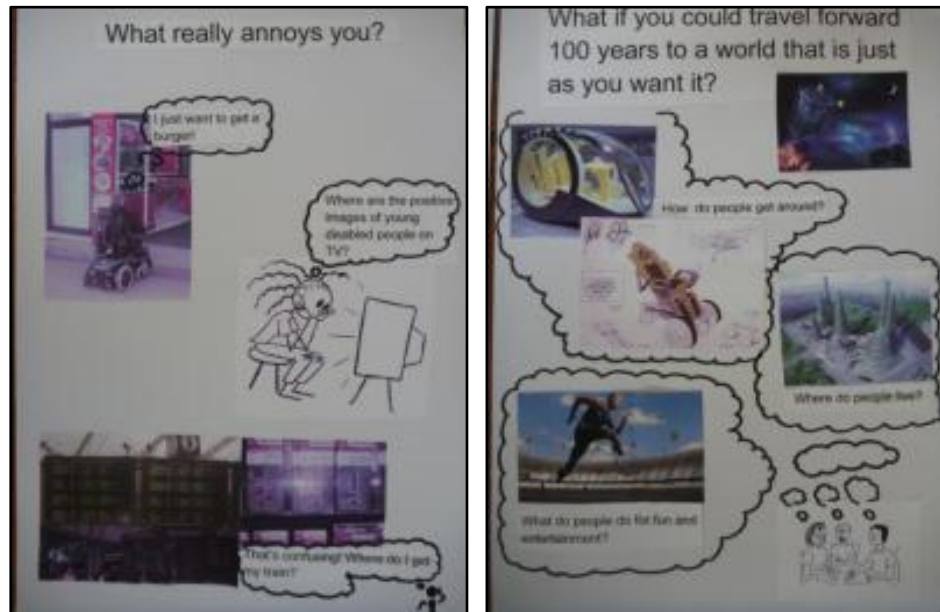


Figure 7 Introductory Posters used in YF

First Futures Workshop

Approximately three weeks after the cameras workshop the first futures workshop ran as follows. On agreement of the young people, I video recorded the workshop (in line with the university's ethical guidelines, the video was later transcribed and destroyed). Gibson-Graham (1999) highlights the importance of looking for moments of 'otherwise' thinking within dominant discourses which can lead to hope and positivity, rather than feelings of despair and hopelessness. Drawing on this, I took with me two props: my bathroom bin and a handcrafted time travelling post-box (*Figure 8, overleaf*). The young

people sat in a circle and, after reintroducing my research, I began with an intended icebreaker activity. I told the young people that before we could design our best-ever future world we had to work out what annoyed us in the present. I asked each young person to introduce themselves, and share something that had annoyed them recently. I wrote each annoyance onto a postcard which was put into the bin to stay in the past. My plan was to then think about how these things could be different in the future: the positive future ideas would be written onto postcards, but this time posted into the time-travelling post-box and taken to the future. Young people would have the chance to design posters around their imagined worlds. The icebreaker activity, however, generated much discussion, taking the majority of the session. Consequently, I was asked to return to a subsequent YF and run another workshop.



Figure 8 Bin/post-box activity, first futures workshop with YF

Second Futures Workshop

Once again, in the second futures workshop discussion dominated, and time for making posters was limited. This was not a problem for my research, and neither did young people and youth workers conceive it as such. Nevertheless, the beginnings of posters which were made were left with the group, for them to finish and display around the centre. In total, seven and a half hours was spent running workshops with YF.

Colin

I met 22-year-old disabled activist, Colin, at the cameras workshop. Colin is very involved in the DPO that YF is part of; offering peer mentoring and doing consultancy

work around the accessibility of spaces such as museums. He was also part of a group planning to visit schools and talk to students about ‘disability’. Enthusiastic about my research, Colin asked if he could get more involved. Since this time I have got to know him independently of YF. We initially met up twice in December 2012 for recorded interviews/conversations (which were later transcribed, and the recordings destroyed). The first discussion began by me asking Colin what his best-ever future world may look like. After two hours of chatting, however, we had strayed away from utopian visions, and Colin told me of the oppression he faces as a disabled young man. Colin also informed me that with the help of the DPO he was in the process of hiring his first PAs, and looking for accommodation independent from his parents. The second recorded conversation therefore focused upon Colin’s views around disability and ‘independent adulthood’.

Colin and I have since remained in contact, spending time together as friends, outside of research. Davis (2000, 192) writes that ethnography “provides countless possibilities for the ethnographer to provide his/her respondents with the opportunity to question his/her analysis. The researcher’s and the respondents’ assumptions and interpretations are subjected to daily review”. Like with the young people in Iceland (addressed below), I would talk through analytical points with Colin (either in person or via email or phone) as part of my wider ethnographic project (Davis, 2000; Okely, 1975). As well as the introductory posters outlined above, Colin also looked over the ‘accessible summary’ (*Appendix Seven*) for me before I returned it to Explore and YF. Colin came to two conferences during the project. We together attended *Time to end the bias towards inclusion?* hosted by *Manchester Metropolitan University (MMU)* at the *Museum of Science and Industry* in November 2011. I asked Colin if he would consider presenting at the *Child, Youth, Family & Disability Conference* held at *MMU* in May 2012, to which he agreed and delivered a keynote presentation. I introduce Colin further in *Chapter Six*. Overleaf is a timetable detailing the various meetings and workshops that formed my UK fieldwork.

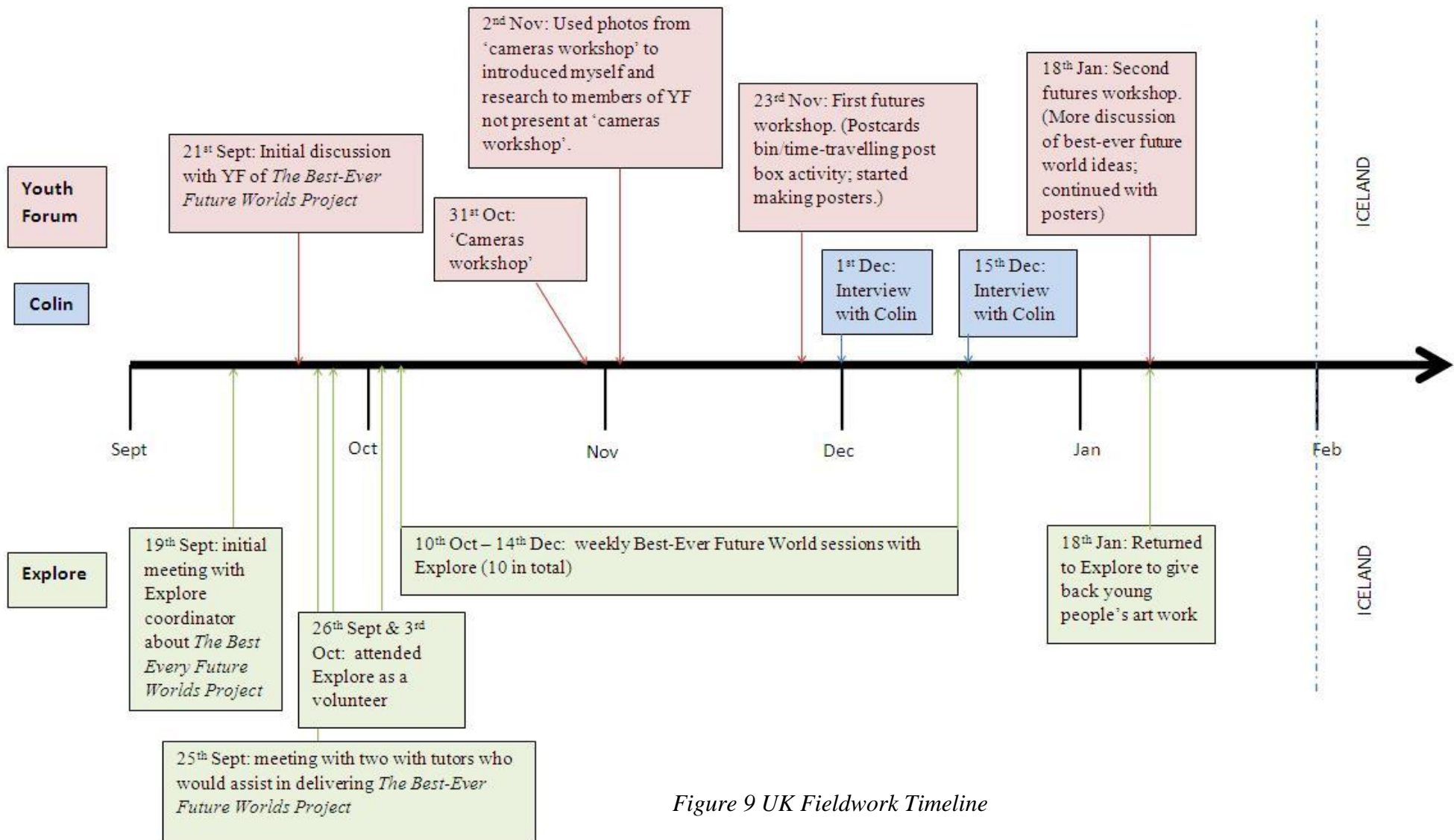


Figure 9 UK Fieldwork Timeline

Iceland

My three month ethnography in Iceland was directly subsequent to UK fieldwork, spanning February, March and April 2012. Much time was spent with disability activists, Embla Ágústsdóttir and Freyja Haraldsdóttir; both of whom work at the Independent Living Centre (ILC) in Reykjavik. I initially encountered the women in 2010 when they were keynote presenters at *Theorizing Normalcy and the Mundane 2010* at MMU. This was the first conference I attended. I was an undergraduate student and blown away by these young women, but too shy to introduce myself. It was not until May 2011 when I attended the *Nordic Network of Disability Research (NDR) Conference*, hosted by the *University of Iceland (HI)* that we were properly introduced. During my week in Reykjavik the seed was planted to spend time as a visiting researcher at the *Centre for Disability Studies* at HI; giving me the opportunity to continue my ethnographic research with young disabled activists. I received ERASMUS funding which made this possible. I will introduce you to Freyja and Embla, before turning to detail my time in Iceland.

Freyja

Freyja is 25 and her fights for disability rights have made her a celebrity in Iceland. In 2007 she published a book, *Porcelain* about the prejudices she faced growing up as a disabled young woman. After publication Freyja travelled around every school in Iceland to talk to students and teachers about her experiences. Freyja's academic interests are in children and disability; her BA thesis looked at interactions between professionals and parents in the hours and days subsequent to a disabled child's birth (a topic she hopes to extend to PhD level). After long and public battles, in 2011 Freyja won the right to 24-hour personal assistance.

Embla

Embla was 21 during my visit. Despite her involvement in the academic world, where her interests are gender and disability, Embla had not yet begun studying for her undergraduate degree. She was studying for her final high school exams during my stay. Embla is currently battling for funding to increase the hours of personal assistance she is entitled to.

Embla was 16 when she first encountered Freyja. She sat in her school, listening to Freyja speak as part of her book tour. Embla told me that this was the first time she had heard another young disabled women talk of experiences that resonated so strongly with her own. Unsurprisingly, it had a massive impact (the importance of disabled role models for young disabled people becomes apparent in *Chapters Seven* and *Eight*). At the time, however, Embla was too shy to approach Freyja. It was not until 2010, on their trip to keynote at *Theorizing Normalcy and the Mundane* in Manchester, that the two women became friends.

The ILC

Around the time of the Manchester conference Freyja was setting up Iceland's first (and only) ILC; a user-controlled cooperative for personal assistance in Reykjavik. Whilst in Manchester, Freyja persuaded Embla to get involved. Since this time, Freyja and Embla have both sat on the board of the ILC. As the managing director, Freyja is the only fulltime member of staff and paid employee. Embla works (voluntarily) part-time, as the chairwoman.

During my stay the ILC was under significant financial constraint and Freyja was without wage while the girls fought tirelessly to establish funding. There were worries about the ILC's longevity. I consider the aims of ILMs in relation the adulthood signifier of independence in *Chapter Seven*. For now, however, I offer you this summary of Iceland's ILC, from their recent publication, *Free*:

“The cooperative is based on the principles of the Independent Living philosophy and the European Network of Independent Living (ENIL) requirements for membership. The purpose of the centre is to assist disabled people in recruiting and organizing personal assistance through peer support and take responsibility for all the administrative work. Also it is to offer training to personal assistants, the public and the government about the Independent Living philosophy and participate actively in international collaboration concerning Independent Living.”

(Haraldsdóttir & Sigurdardttir, 2011)

Girls' Group: Breaking through Limitations

In 2009 Embla was funded by the *Youth in Action Programme* of the *European Union* and the *Human Rights Office* to run a three month course for disabled girls between the

ages of 10-13 called Breaking through Limitations. The group met twice weekly. One session would be 'discussion based'; Embla used methods of informal education to introduce the young women to political movements including disability rights, independent living (IL) and feminism. In the session next the girls would themselves organise and partake in a particular activity (horse riding, rock climbing, and finally, spending a weekend at a summer house in the countryside). Girls were encouraged to explore their gendered, sexual and disabled identities. Embla wanted to promote confidence building and self-expression, provide a safe space for the girls to 'be disabled teenage girls' and spend time with other young disabled women.

I was in email contact with Embla and Freyja since we first met in May 2011. I had discussed with them my potential visit and research interests. Both women were keen to be involved. Embla and I met in September 2011 when she visited the UK. Embla told me that she and Freyja were hoping to re-establish Breaking through Limitations during my visit. It would be comprised of the original set of girls, who would now be aged 13-16. I was keen to be involved.

Evolving Research Plans in Iceland

Before leaving for my ERASMUS funded trip to Iceland my plans were:

1. To introduce my work at the *Centre for Disability Studies* at *HI. Rannveig Traustadóttir* headed the centre, whose work I had come across in relation to gender, child, family, youth and disability (Traustadóttir, 2004). I was keen to receive feedback on my own work from a new research community with similar interests.
2. To attend conferences and seminars, where opportunities arose.
3. Although it was not clear before my departure when Breaking through Limitations would be established, I hoped to attend and participate in meetings. Perhaps introducing some of the creative methods I had employed with Explore and/or YF, with another group of young people.
4. To interview Embla and Freyja. Like with Colin, my starting points for interviews would be 'talking utopias'. I was interested in Sargisson's (2000) suggestion that people involved in political movements are already 'utopian thinkers'. However, I was also happy for interviews to take a 'conversational' tone, and be led by participants (Oakley, 1981).
5. As my analysis of Explore and YF data had started at the beginning of fieldwork (Charmaz, 2000), I hoped to talk about themes that had arisen in the UK with Embla and Freyja, specifically in relation to:

- a. What independence means to young people involved in ILMs (addressed in *Chapter Seven*).
- b. How gender and sexuality related to youth and disability (gender, sexuality and disability being a passion of Embla's).

Ethnography is a continuous and reflexive process (Ellis & Bochner, 2000; Tedlock, 2000). Inevitably, therefore, my plans changed. Tedlock (2000) writes that fieldwork became inseparable from the physical and emotional lives of early ethnographers, as they ventured abroad to immerse themselves in foreign cultures. She cites Elwin who in 1968 wrote, “for me, anthropology did not mean ‘field-work’: it meant my whole life” (Elwin cited in Tedlock, 2000, 458). Although Iceland did not seem ‘foreign’ as in the colonial depictions offered to us by early ethnographic researchers, for me, it was nevertheless a scary endeavour. I was taken aback, however, by the generosity and welcoming attitudes I was offered by Embla, Freyja and those at the *Centre for Disability Studies*. Perhaps due to the intensity of leaving regular support networks I felt I got to know Embla and Freyja quickly. After my first two weeks in Iceland I was overwhelmed by the amount I was learning from Embla and Freyja, not through any kind of research relationship, but through our social ‘hanging out’. As discussed by Jackman (2010) and Lawthom (in Goodley, Lawthom, Clough, & Moore, 2004), my relationships with Freyja and Embla rapidly became more than researcher and researched. Although we were already colleagues, and I would have further conceptualised our relationship as comrades, very rapidly my most important affiliation to the women became (and remains) as friends.

I met with Embla and Freyja almost daily. I was welcomed into the women’s ‘saumaklubber³’. We drank coffee, ate and went to concerts. I was introduced to their Icelandic friends and comrades. I spent time with disabled children, young people and their parents, as well as others working or with an interest in CDS. I regularly met for coffee with the chair of Iceland’s self-advocacy group who, after being involved in an inclusive research project had become involved in CDS and had strong views on what accessible and inclusive research should look like (Björnsdóttir & Svendsdóttir, 2008). They were my social, as well as research circle; and with every interaction I was thinking again about my data, and my relationships with youth and disability. This, of course, brings with it its own ethical dilemmas (Ellis & Bochner, 2000; Tillmann-Healy, 2003) which I discuss further in the ethics section below.

³ Translating to ‘sewing club’, this is a time where Icelandic women traditionally get together to sew, though nowadays sewing rarely takes place, rather women eat, drink and chat together.

To conduct interviews as I had planned therefore seemed both tokenistic and staged. I would have been seeking to replicate conversations we had already had informally, but adding the gaze of a Dictaphone (Oakley, 1981). I instead used the 12-week period as a time of reflexive ethnography to think-through ‘youth’ and ‘disability’, and relate what I was learning to my research questions (Ellis & Bochner, 2000). As discussed in ‘dealing with data’ below I relied heavily on my research diary. This resulted in 87 A4-sized pages of handwritten research notes which were recorded over the following settings:

1. Conference and seminar attendance:
 - a. Weekly PhD meetings at the *Centre for Disability Studies*, including presenting and receiving feedback on my work.
 - b. A conference introducing a new law around IL in Iceland. Freyja and Embla presented here, and I draw upon their presentation in *Chapter Seven*.
 - c. A conference around IL, specifically for people labelled with intellectual impairment, also drawn upon in *Chapter Seven*.
2. Attendance and participation (to the extent language barriers would allow me) with three meetings of Breaking through Limitations . Each meeting was three hours long.
3. Numerous social events with Embla, Freyja and their friends; dinner parties, cinema trips, visiting bars, going shopping, drinking coffee, watching films.
4. Three coffee-drinking sessions with the chair of Iceland’s self-advocacy group (lasting between one and three hours).



Figure 10 Embla and I on a trip downtown



Figure 11 Freyja, Embla and I having dinner at my apartment

After I had attended the introductory meeting at Breaking through Limitations I decided it would be inappropriate for me to run sessions similar to those employed in *The Best-Ever Future Worlds Project*. Although all young people involved spoke English (to different degrees of fluency), the group was run in Icelandic; for me to impose my English seemed presumptuous. In the sessions I attended Embla, Freyja or one of the participating girls would translate for me. However I felt a) that I missed some of the subtleties and banter of conversation, often feeling alienated from the group and b) somewhat of an inconvenience, separating the translating individual from the group dynamics. Thus, although I found the sessions I attended useful and interesting (drawn upon in *Chapter Eight*), I decided after the three sessions to terminate my attendance. Instead, Embla would feed back to me what had happened and share with me the material she had used with the group.

Language Barriers

The two conferences listed above were, at least in part, conducted in Icelandic. I became reliant on ‘whisper translation’ from friends in attendance. Although in some ways this was a disadvantage, there were also positive aspects. Textbooks of ethnography tell us the importance of establishing rapport with participants (Geertz, 1993). Although I may have missed some information given by the speakers, I felt translation strengthened relationships and friendships between other translating delegates and myself, opening more informal discussion around conference themes.

Ethics

Ethics happen on various levels. As outlined in the introductory chapter I would not be conducting research unless I considered it an ethical endeavour. My research is politically motivated; it sits with my personal, subjective ethical position that society could and should be a more inclusive place for us to become-in-the-world-together (Shildrick, 2009). I think about how this can be achieved by looking at the intersection between ‘youth’ and ‘disability’. I begin my ethics section broadly, by discussing ethics alongside disability politics. I then discuss micro-ethical concerns, those Guillemin and Gillam (2004, 263) term ‘procedural ethics’; the ethical procedures that I have adhered to in order to gain *MMU* ethical approval. My discussion of the close friendships developed in Iceland brings with it a host of ethical dilemmas. I consider the ethics of friendship within ethnography. Finally, I explain how I endeavoured to leave the research field, ethically.

Ethics and disability politics

Goodley and Lawthom (2005) highlight eight questions disability researchers are asked in relation to research. One involves partisanship: “whose side is the disability researcher on?” (cited in Goodley, 2011, 23). Like Goodley and Moore (2000, 826) my political commitments begin “firmly on the side of disabled people”. This effects what I consider makes research ‘ethical’. Goodley and Lawthom (2005) also highlight praxis: “does disability research make a positive difference in the lives of disabled people?” (cited in Goodley, 2011, 23). Research question one asks: what dangers do young disabled people face if normative discourse remains unquestioned? We have already seen some of these dangers over *Section One*: paternalism resulting from ableist signifiers of adulthood (*Chapter One*); violence and disposability when disabled people are not consider useful producers and consumers (*Chapter Two*); gendered discourses of idealised bodies positioning young disabled people outside conceptions of ‘youthfulness’ (*Chapter Three*). Through and with the lives of young disabled people, I consider how we can think differently and more inclusively about youth and adulthood. As Goodley (2011, 27) puts, if, as CDS researchers, we do not aim to seek and counter disablist prejudice, “why bother?” My commitment to an emancipatory politics of youth and disability affects my conceptions of ‘ethical research’. I respond to two more of Goodley and Lawthom’s (2005) questions, inclusivity and accountability, below in relation to my own project:

1. Inclusion: “to what extent does research include disabled people?” (Goodley, 2011, 23)

There is contention over what constitutes ‘emancipatory research’ (Barnes, 2002). I do not attempt to fit my work into an emancipatory framework. More relevant to my project are broadly defined participatory approaches. Participatory research has emerged in a range of disciplines aiming to meaningfully include traditionally objectified and excluded groups, and has been taken up in disability research predominantly when attempting to include people with labels of intellectual impairment (Walmsley, 2001). Unlike emancipatory research which demands research to be in full control of disabled people (Barnes, 2002), participatory disability research emphasises co-research between disabled and non-disabled people (Chappell, 2000; Priestley & Stone, 1996; Zarb, 1992). Participatory research is inclusive to differing levels: from ensuring all information is accessible, to devising research questions and involving disabled people in analysis and dissemination (Björnsdóttir & Svendsdóttir, 2008; Burke et al., 2003; Liddiard, 2012; Goodley & Moore, 2000).

Neither, however, do I consider my project to be fully inclusive. I entered all strands of research with an agenda: to ask young disabled people what their best-ever future worlds would look like in the hope of exploring my research questions, which were set by me, not participants. Nevertheless I strived to make parts of the project that young people participated in, namely the ‘data collection’, as inclusive as possible. I have already hinted at some of the ways I went about this through my description of the three research contexts above. I make concerns explicit overleaf (*Figure 12*) in terms of Explore and YF, as I address Icelandic research specifically later in the chapter.

Aim	Example/Practice	Concerns
To explain my research in an accessible format	<p><i>PowerPoint</i> presentation sent out to groups (included on <i>DVD 1</i>) – minimal text read out by voice over, played on single click.</p> <p>Posters used to introduce my research to YF (<i>Appendix Eight</i>) – minimal text, pictures, large font. Checked with Colin for accessibility.</p>	<p>Relying on adult gatekeepers to pass the <i>PowerPoint</i> presentation onto participants.</p> <p>Patronising?</p>
Ensuring ‘research tools’ and activities remained accessible and meaningful in Explore	<p>Spoke to art tutors who knew the young people well before starting the project</p> <p>Spent two sessions as a volunteer to get to know the young people</p> <p>Young people completed <i>Reports from the Future</i> in their preferred format (paint, text, drawing etc.)</p> <p>Individual instructions from time travelling guru rather than ‘one size fits all’ approach</p> <p>Flexible approach to data collection: from envisioned group art piece, to individual at request of group</p> <p>Young people were asked (or requested) to be interviewed in format of their choice: more ‘traditional’ interviews; recorded conversations; ‘newsflash-style’ (outlined above). Some were not interviewed at all.</p>	<p>Initial conversations with adult gatekeepers, rather than young people</p> <p>Some instructions from the time travelling guru dictated more than others – restricting creativity based on my own/art tutors conceptions?</p> <p>Sometimes felt like the artwork was not answering my research questions, although the conversations I was having with young people were (hence valuing processes within larger ethnographic project)</p> <p>Young people coming in at different times and busy noisy atmosphere meant I did not remind young people of my research aims at the beginning of every session, although I did try reinforce it through conversations with individuals</p>
Ensuring ‘research tools’ and activities remained accessible and meaningful in YF	<p>Attempted to balance the ‘social model’ aims of YF with my own agenda as a researcher (illustrated in ‘cameras workshop’ scenario earlier)</p> <p>Used Colin as an ‘accessibility consultant’ after cameras workshop to ensure accessibility of the posters used to further outline the research</p>	<p>Are young people restricted to not bring up conversations outside of disability?</p> <p>How much am I letting young people lead the research, and how much is being led by youth workers?</p> <p>Why do I assume Colin knows if information is accessible? (I don’t, but he knows the group better than I do, and he has a good social model nose for issues of accessibility)</p>

Figure 12 Ethical Concerns with Explore and YF

2. Accountability: “who are disability studies researchers accountable to?” (Goodley, 2011, 23)

The question of accountability is particularly pertinent as a non-disabled researcher (Oliver, 1998; Priestley & Stone, 1996). Concerns have been raised within disability research that non-disabled researchers researching disability issues further their own careers rather than championing the rights of disabled people (Oliver, 1998). I tried to balance my own agenda as a researcher with young people’s and (in the case of YF) organisations’ interests and priorities. It would be fictitious to claim young people took a lead in research, yet I ensured ‘room for manoeuvre’ within the activities I presented them with. Furthermore, I tried to make activities enjoyable and, in the case of Explore, tailor them to young people’s particular interests.

Some argue that the already asymmetrical power relationship between researcher and researched are heightened when the researcher is non-disabled (Barnes & Mercer, 1997). I outlined earlier my occasional discomfort in my non-disabled researcher status within YF, a disability organisation working along ‘social model’ lines. However, the scenario also illustrated that not just disability, but other axes of identity were at play. At specific times of data collection, I felt relatively powerless compared to that of the youth workers (particularly, the middle-aged man). Nevertheless, once I had left the research scenario, in possession of the words and stories of participants, my powerful position was reinstated. I was, in effect, free to ‘use’ data I had collected, abstract it from young people’s lives, into a format inaccessible to them (Larson, 1997). To an extent, this is what I have done. At this stage, dissemination of my research is largely through this thesis, in a format inaccessible to the majority of participants. I took various steps, however, to remedy this (to a degree), by making myself accountable to my young disabled participants.

Concern	Action	Result
That young people could ask me about my research	<p>I told young people they could ask me anything about my research, at any point during the process. I tried to make myself available for questioning. All had my email address, in case they preferred email to face-to-face conversation.</p> <p>In line with Explore policy, parental consent was sought. Therefore, parents also had my email address so they could contact me with questions.</p>	<p>In YF lots of questions were asked (by both youth workers and young people) about my research. In Explore, however, artwork took the focus. I therefore made a conscious effort to talk to and ask young people's opinions on my research (even where sometimes I felt I was boring them!).</p> <p>Continual contact with Colin about my research since we met.</p> <p>One mother from Explore has been in email contact, as have the youth workers at YF.</p>
Ownership of data	Although subsequent analysis abstracts the data from young people's lives, I wanted young people to have a product of research.	<p>Explore: each young person has their own individual art piece, which were returned to them.</p> <p>YF: posters were made to represent their future worlds which could be displayed at their centre.</p> <p>All young people received an accessible summary.</p>
Analysis	Although I did not involve young people in analysis, I discussed analytical themes that had arisen with Colin, Embla and Freyja.	Dealt with further below.
Dissemination	I made accessible summaries (<i>Appendix Seven</i>), which I asked for Colin's opinion on in terms of a) accessibility and b) content, before distributing to YF and Explore.	<p>I returned to Explore with accessible summaries for young people and staff. One parent found the summary in her son's bag and requested a PDF copy, which I sent her.</p> <p>YF could not accommodate a return visit due to their busy schedule. In lieu of a return visit, I emailed them a copy of the</p>

	<p>All young people invited to attend <i>Child, Youth, Disability and Disability 2012</i> conference where I spoke in relation to my work.</p>	<p>accessible summary, which they distributed amongst young people. I remain in email contact with youth workers at YF.</p> <p>Out of UK participants, only Colin took up my invitation, and he delivered a keynote address.</p> <p>I co-presented with Embla and Freyja (detailed below).</p>
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Figure 13 Balancing Power with Explore and YF

Procedural ethics

I gained and have adhered to the guidelines of *MMU Faculty Ethical Approval*.

Guidelines stipulate the receipt of informed consent. For the groups I was working with it was important to explain the project in a variety of ways. Thus how I gained consent varied dependent on context. I explained the research through individual and group conversations; participant information sheets (*Appendices Nine and Ten*), and with the aid of the various posters and DVDs (outlined above). All participants signed consent forms (*Appendices Eleven to Fourteen*). As Icelandic participants were fluent in English, it was not necessary to translate consent forms into Icelandic. I explained consent forms individually with members of Explore and my Icelandic comrades. With YF we discussed the consent forms as a group before the two youth workers, personal assistants (PAs) and I worked through the forms individually with young people where appropriate. Explore’s own policies required that young people’s parents were also provided with information sheets and asked to sign consent forms. All names in the UK are pseudonyms. Embla and Freyja both chose for their real names to be used (for various reasons discussed below). Aside from Freyja and Embla, all other Icelandic names are pseudonyms.

I ensured that all young people knew they could withdraw consent at any point during the project. I reintroduced my project at the beginning of each YF workshop, and checked the young people still wanted to participate. I also rechecked that they did not mind me recording the session. As sessions were less structured at Explore I was unable to reintroduce my project at the beginning of every session. I therefore made a conscious effort to talk to young people (individually or in small groups) about my project as they

busied themselves with their work; reminding them what I was doing, and checking they wanted to participate.

In line with MMU's ethical guidelines, all data which could reveal personal information was kept securely. I made two copies of each video recording from the YF: one on DVD, and another saved directly to my computer. After transcription the latter was destroyed, whilst the former was kept securely along with other data.

Ethics, ethnography and friendship

I have perhaps neglected the most ethically difficult parts of my fieldwork in the above discussion; that is, the ethical dilemmas faced when friendships and research situations could not be separated from one-another. Goodley (1999, 39) tells us that “[t]here is more to ethnography than simply observing. Feelings are reciprocated as relationships grow”. Researchers and participants interact to produce data, and “all interactions involve moral choices” (Tedlock, 2000, 455). Changing relationships happened in all contexts of my fieldwork. I felt an allegiance to all young people who offered me their views and experience. With Colin feelings were more acute than with other young people in the UK, as what began as a research relationship extended to a friendship, and we pursued activities together outside of YF. However, I never felt uneasy in distinguishing between what was ‘research’ and what was ‘other’: mainly because even when conversations involving disability happened outside of the two recorded conversations we had (which they often did), the topics had already been raised in these more formal settings. Furthermore, our hanging out was always one-on-one, it was therefore easy to ask Colin if it would be okay for me to include a particular idea of story in my research at the time topics were raised.

In Iceland, however, things felt more complicated. In the introductory chapter to my thesis I wrote of the importance of constantly queer(y)ing my emergent ethical position (Ellis, 2007) and never was this more important than during my stay with Embla and Freyja. Unlike with Colin, during my time in Iceland Embla and Freyja were not one amongst friends, but my closest friends and friendship group. Goodley (1999) writes of his transitioning positionality between a volunteer and researcher in self-advocacy groups. He writes that “when social contexts become research contexts, they are changed” (Goodley, 1999, 36). Yet, with Embla and Freyja, it was not so much a social

context becoming a research context, but research and social contexts colliding and complementing one-another. The time we spent together was both socialising and research. This was exhilarating and thoroughly enjoyable, yet, also worried me:

“I’ve just got back from dinner at Freyja’s. Hanging out with such engaged and confident women is brilliant: I think it’s the most comfortable I’ve felt in a group this early on. I feel slightly overwhelmed by how generous, welcoming and open they’ve been. And I’m learning so much!”

(Research diary 13th February 2012: after dinner and Eurovision finals at Freyja’s apartment)

“Had some good chats with Embla and Freyja tonight. We watched ‘*Scarlet Road: A Sex Workers Journey*’ (Scott, 2011) and ended up chatting about all sorts of things: sex, disability, notions of independence. I’m not sure I should write them down though, it was ‘girly chat’ (Ellis, 2007), not research.”

(Research diary, 16th February 2011, after watching *Scarlet Road* at Freyja’s apartment)

In nearly every conversation with Embla and Freyja I was thinking again and learning something new about my research. Some of this felt okay: we informally discussed the politics of disability and ILMs, and I had no qualms about including this in my work. Spending time with them to challenged my own notions of independence (further addressed in *Chapter Seven*); topics that Embla and Freyja both speak publically about and are important to be discussed. The latter quote from my research diary, however, shows that there were parts of my learning that blurred lines of friendship and research, which made me anxious.

Tillmann-Healy (2003) uses the term ‘friendship as method’. On a ‘guttural level’ it turns me off; although perhaps not the intention of the author, for me, the term reduces friendship *to* method; making ‘friends’ in order to further our own research and academic careers. I have already highlighted concerns around non-disabled people doing disability research to benefit their own careers (Oliver, 1998). This was certainly *not* my intention with Embla and Freyja. My friendships with Embla and Freyja were an organic result of getting to know one-another, this happened to be in a research context. Evolving friendships at times aided, and at other times hindered my research. Nevertheless, they developed to mean far more to me than any research agenda, or, for that matter, academic career. Ellis (2007, 9) talks about learning from “girl talk” when conducting ethnographic research with fishing communities: discussions of “family, including pregnancy and

child birth, menstruation, sexual relationships, premarital and extramarital sex, sex-related diseases and problems”, all topics she included in her book. When this book was returned to the communities which she had formed close friendships within, there was anger at the portrayals Ellis presented. Reflecting on the research, Ellis admits she made ethical mistakes, however, she wonders how it is possible to make research agendas apparent in every interaction with groups you now consider friends. This was a warning to me, yet, I could not help feeling similarly. Unlike with Colin, conversations in Iceland were not just on a one-on-one basis, but amongst groups of friends. I could not stop the banter midway and to ask if it could be included in my project.

The answer in the end was to speak openly to Embla and Freyja about my concerns. The timeline overleaf (*Figure 14*) visually represents working through our ethical dilemmas, including the solution we together came to around mid-March. I stress this below:

1. I would continue to record my thoughts, feelings, and the stories Embla and Freyja told me in my research diary.
2. Before writing up, or sharing stories with anybody else, including my supervisor, I would discuss with them the particular story I wished to use, and for what purpose.
3. On agreement, I would write this up in first draft form, and send this to them. Giving them the opportunity to edit or remove the story.
4. If Freyja and/or Embla were happy with it, I would then have permission to share it with my supervisor, before writing the final version.
5. Again, I would send Freyja and Embla a copy of the final chapter which their story featured in.
6. I would check with them again before I used any stories in papers for either publication or presentation.

Embla, Freyja and I also discussed the possibility of using pseudonyms. However, within the small populations of Iceland and the CDS community, Embla and Freyja are relatively well-known; to use pseudonyms would be tokenistic. Moreover, they were both keen that their names were attributed to their stories.

Denzin (1998, 320) writes that “even when “we” allow the Other to speak, when we talk about or for them, we are taking over their voice” (320). Concurring with Denzin’s conviction (considered further in ‘dealing with data’) we found co-writing an ethical way to approach more sensitive topics (Ellis, 2007). Before leaving for Iceland I had mentioned to Embla and Freyja the *Child, Youth Family and Disability 2012 Conference*

at *MMU*. To my delight, both decided to attend. This conference seemed a good opportunity to voice some of the conversations we had been having. The paper (Slater, Ágústsdóttir, & Haraldsdóttir, 2012) focused upon the different expectations placed upon Embla, Freyja and I as young women growing up in terms of gender and sexuality. The topic meant we could all share the stories we felt okay to talk about publically. We were all exposing our vulnerability for, what we considered to be sound and important political purposes. Furthermore, we all felt we had something to gain from sharing these stories, in terms of our academic careers and personal politics. The process of co-writing was useful to a) ethically generate further data (Richardson, 1998); and b) verify some of my thoughts with my disabled comrades.

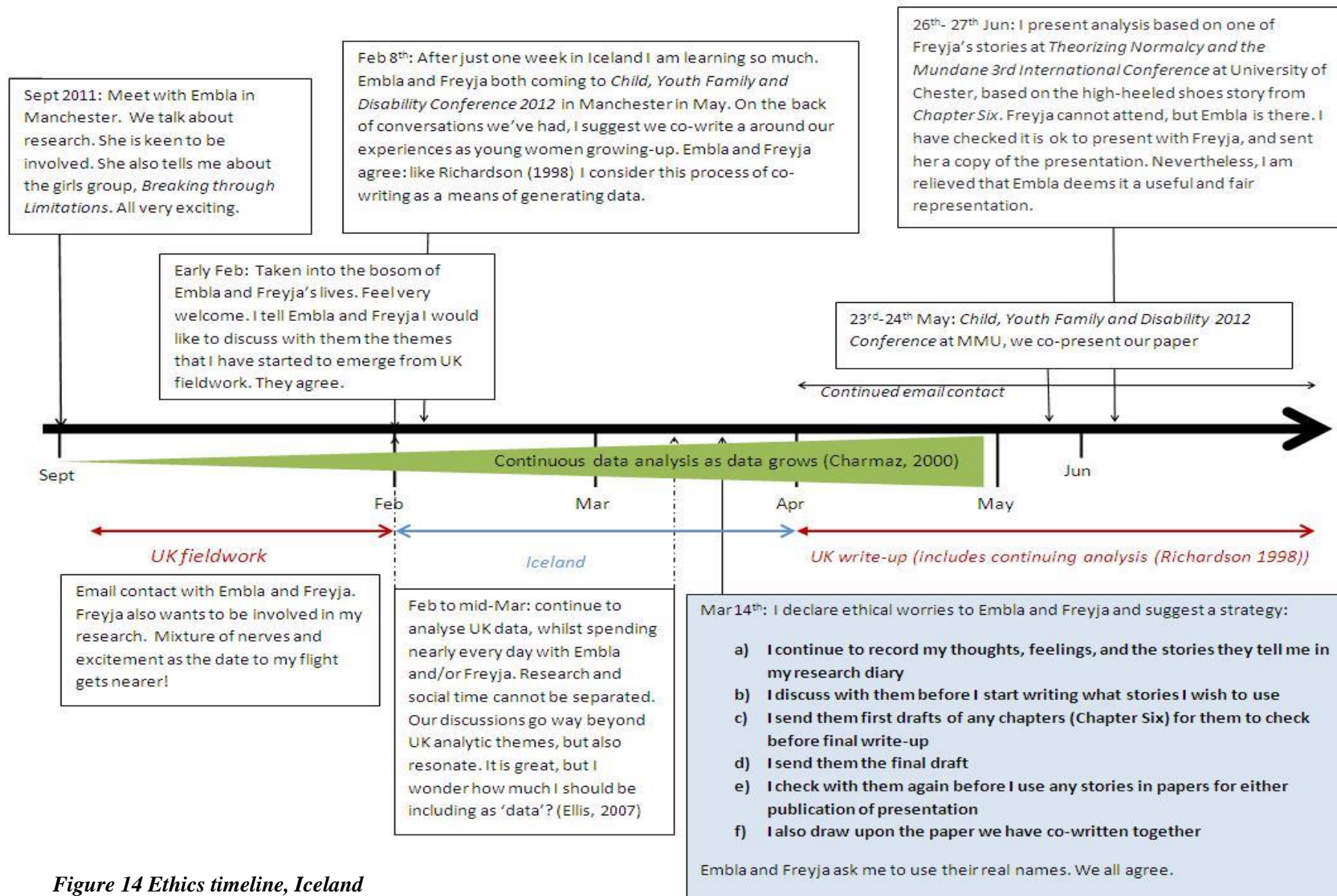


Figure 14 Ethics timeline, Iceland

Ethically leaving the field

Tedlock (2000) writes that, for early ethnographers, fieldwork was not just the centre of their intellectual, but also their emotional lives. They were accepted into communities, but with the sole intention of leaving. 'Leaving the field' for me meant different things in different strands of my research.

Explore

'Leaving the field' arguably happened most conventionally with Explore. Although I remain in contact with the group, and have already visited on several occasions since my project ended (once to return with young people's artwork, and later with the accessible summaries), I wanted to ensure I marked my departure at the end of the research period, for my own sake, as well as the young people's. I presented the young people with certificates and chocolate in an (inadequate) attempt to thank them for their time. Projects with Explore generally run in 12-week blocks, so moving on from one project to the next was in line with a usual chain of Explore events.

YF

Similarly, the young people in YF were used to the transiency of people coming in to run one-off workshops, so my guest presence was not unusual. Nevertheless, I felt an affiliation to the group, and was pleased at the end of the second futures workshop to be invited back to run future sessions with them. Unfortunately, although I have since been in contact, sending the group accessible summaries, due to mutually busy schedules there has not been an opportunity to return.

Colin and Iceland

With some participants, there is "no leaving the field" (Ellis, 2007, 13). I remain in email contact with Colin. We have met up on numerous occasions since my fieldwork finished. As Colin and my Icelandic comrades all attended the *Child, Youth Family and Disability 2012* conference, they all met, and it was great to introduce this group of people. Although my physical contact with Embla and Freyja has lessened, we remain in regular 'virtual' contact, as well as getting back together at various CDS conferences and events.

Rather than ‘friendship as method’, I feel my experience with these young disabled people is more akin to camaraderie through research (and beyond).

Dealing with data

My research was a participatory method of enquiry which allowed me to creatively explore young disabled people’s ideas around youth, adulthood, disability, and how we could becoming-in-the-world-together (Shildrick, 2009). In the 1970s there was a shift in ethnographic thinking; emphasis moved from participant observation, to the observation of participation (Ellis & Bochner, 2000; Tedlock, 2000). Largely feminist voices (Ellis & Bochner, 2000) argued that ethnographic observation was not enough, and ethnographers needed to participate in the cultures they were studying (Davis, 2000; Oakley, 1981). Although all my research contexts demanded different methods, the various forms of participation came together to form my larger ethnographic project. At the end of the research period, I was left with the following:

Explore:

1. Six ‘Reports from the Future’
2. Two ‘A Day in the Life’ timelines
3. Six final art pieces
4. Four recorded and transcribed ‘newsflash’ interviews
5. Six recorded and transcribed informal interviews
6. 27 pages of my own research notes and reflections

YF:

1. 139 photos from the cameras workshop
2. Five beginnings of posters from the first time travelling workshop
3. Eleven nearly-finished posters from the second time travelling workshop
4. A transcript from each workshop
5. 29 postcards of annoying things to be left in the past
6. 10 postcards of good things to take to the future
7. 14 pages of my own research notes and reflections

Colin:

8. Two transcribed interviews/conversations (3 hours in total)

Iceland:

9. 87 A4 pages of handwritten ethnographic research notes
10. A co-written paper between Embla, Freyja and I (Slater, Ágústsdóttir, & Haraldsdóttir, 2012)

I explain how I dealt with this data below.

Explore

Fieldwork with Explore was the first to begin. Like in all contexts, I valued to process of research, time spent imagining with and chatting to young people, as much, if not more, than their final art pieces. With Explore, the process of making final art pieces included the creation of other artwork: ‘*Reports from the Future*’ and ‘*Day in the Life*’ timelines which young people used to think-through their ideas. Like in the other two contexts, however, I also relied strongly on my research diary as a means of both creating and reflecting upon data (Richardson, 1998). Charmaz (2000, 514) writes that “[ethnographic] data are narrative constructions (Maines, 1993). They are reconstructions of experience; they are not the original experience itself”. I used my research diary to construct narratives of my experiences in Explore.

Drawing on Glaser and Strauss (1967), Richardson (1998) suggest categorising field notes as observational notes (ONs), methodological notes (MNs), theoretical notes (TNs) and personal notes (PNs). My approach to note making was more fluid. I used my research diary as a ‘stream of consciousness’. Thorne’s description of his field note writing process resonates:

“Field notes... have a private and intimate character; one can innovate, make false starts, flare up with emotions without feeling an anonymous audience at one’s shoulder... As I write field notes, I push for full description, avoiding sociological jargon, staying close to what I saw, while letting my imagination roam around the event, searching for patterns.”

(Thorne cited in Richardson, 1998, 345/5)

Explore took place on a Wednesday between 4pm and 6pm. I would arrive around 3pm to the café next door. Here I would buy a coffee, open my notepad and record my thoughts and feelings about the session. Although I did not ‘code’ it as such, perhaps these notes were close to Richardson’s (1998, 365) PNs: “feelings statements about the research, the people I am talking to, myself doing the process, my doubts, my anxieties, my pleasures. I do no censoring here at all.” In fact, I did no censoring at any stage of writing my research diary; the censoring came when I considered making my research diary public. As I outlined above in regards to my ethical dilemmas in Iceland, it was at this point I decided what I wanted to in/exclude (Ellis, 2007); checking the notes for anonymity; and considering how they could be made presentable to an academic audience (Ellis & Bochner, 2000).

After a session with Explore I would return to the café and note more thoughts. Although not coded as such, these were arguably a mixture of Richardson's (1998) PNs and ONs. They would include 'thick description' (Geertz, 1993) and would be "as concrete and detailed as I [was] able to make them [...] fairly accurate renditions of what I see, hear, feel, taste, and so on" (Richardson, 1998). Occasionally at this point I would begin to link things up with literature: jotting down avenues I should follow up through reading. Generally, however, it would not be until the next morning that this task would begin. Over breakfast, I would go back over my notes, recording TNs: "hunches, hypotheses, poststructuralist connections, critiques of what I am doing/thinking/seeing" (Richardson, 1998, 365). Often, this would mean moving away from the A5 constraints of my research diary to larger pieces of paper and coloured pens which allowed physical links to be drawn. I would take both my camera and *Dictaphone* along to Explore sessions. When these had been used I would look back through the pictures of artwork I had taken the day before, listen to and transcribe interviews. If I thought it was useful, I would print off pictures or sections of transcription, sticking them in and amongst recordings from my fieldwork diary. Data redecorated the walls of my flat.

YF and Colin

I similarly relied on (a different) research diary with YF. The process would work along the same lines as with Explore, recording my thoughts and feelings both before and after workshops (PNs and ONs, if you like) and then going back over them the next morning to jot down theoretical links (TNs). In ethnography, analysis is an on-going, iterative process, which begins from day one (Charmaz, 2000). As there was overlap between the times I was conducting Explore and YF fieldwork links began to be made between the two projects; the pieces of paper got bigger, and the redecoration of my flat more intense.

In the two futures workshops there was a host of additional material to deal with. I found it useful to transcribe video recordings; and did this over the couple of days subsequent to workshops. Similarly, I transcribed the interviews I had with Colin. The process of transcription meant an active process of going back and forth through the data (Mason, 1996). For me, the more passive process of watching the videos back would not have achieved the same immersion in data, as my attention would have wandered. Moreover, transcription meant I was able to print out, physically cut up and move around sections of transcription as themes emerged (addressed below). In the case of the first futures

workshop, where the postcards activity took place (see *Figure 6*), I typed all the annoyances and alternative future ideas into a word document. Although I experimented with ‘*Stickynotes*’ software, I found it more useful to copy the postcards onto physical ‘*stickynotes*’ and stick onto transcriptions.

Iceland

My research diary was relied upon most heavily in Iceland, resulting in 87 A4 pages of handwritten ethnographic research notes. My routine on a morning was to head straight to my local pool. Icelanders tell me their outdoor geothermal-heated pools are the equivalent to the British pub; places not for swimming, but meeting and socialising; to be the public house philosopher, minus the intoxication. For me, the pool was the place to collect my thoughts on how research was going, and, on return, jot these down over breakfast. I often recorded in my research diary several times more each day, reflecting on a specific event, writing down an analytical point or link with literature that had not previously occurred. Here my recordings were most fluid and unstructured; getting messier as I drew links to both literature and UK data. Again although I did not code my notes as such, visible on reflection are a stream of PNs, ONs, TNs, and more-so than in other research contexts, also MNs: “messages to myself regarding how to collect “data,” – who to talk to [...], and so on” (Richardson, 1998, 365). This can be seen in the quote from my research diary below which I have retrospectively annotated:

PN “Everything’s so overwhelming... I’m learning so much, but must be missing so much too – bloody language barriers. The girls group was frustrating. But yet fascinating when **Embla**
ON translated for me - should read Garland Thomson (2002) thing about inadvertent activism again .
TN Also talk to Embla about feminist-disability theory – see what she thinks of RGT/ if shes’ read anything interesting. How different is the girls group Freyja and Embla run to YF? Both activist,
MN but Iceland group more about role models – more chance to think outside of disability, inadvertent activism? Yet similar discussions – we’re the same as everyone else! Links with normative youth literature? – Anna’s [girl from group] comment from the other day – disabled people should do the educating OF COURSE! (look at 7th March notes)”

(Research diary, 10th March 2012)

Charmaz (2000) tells us that data coding is a way to organise data so not to be overwhelmed by it. Furthermore, it is a way to keep the researcher studying their data: to keep that data alive. Although I did not use coding, I was aware that valuable snippets could be lost in the vast amounts of data generated through my writing and reflections

(Richardson, 1998). Each Friday in Iceland I would therefore go back through my notes from that week. On a separate piece of paper I would jot down things that remained significant, pointing myself to particular days and events, which I physically bookmarked. This piece of paper would then be stuck into the back of my research diary. As well as a daily/hourly account running through the front was a week-by-week recording of my time running along the back.

As already made clear, the ONs in my research diary were *my* versions of events, (often) recorded from memory, as *I* had seen them. As soon as any event is recorded is it abstracted from its original source (Charmaz, 2000; Denzin, 1998; Silverman, 2000). In Iceland, however, stories recorded were often translated accounts. There was arguably an additional level of abstraction. In *Chapters Seven* and *Eight* you will see that sometimes my research diary included stories told to me in English by Embla or Freyja, about a conversation they had had with another person. Sometimes I wrote my own dialogues, formed out of stories I was told, as these seemed to represent situations more clearly (Richardson, 1998). Even when an event happened in my presence, I was sometimes reliant on immediate translation or subsequent retellings. This could be considered a weakness in my approach to data collection (Mr Reasonable, I am sure, would think so). However, as Denzin (1998, 319) writes: “the Other who is presented in the text is always a version of the researcher’s self”. My story of another’s story, I argue, is not so different from other ethnographical accounts, albeit that I make the process of abstraction clear. In ethnography “the researcher composes the story” (Charmaz, 2000, 522). I recorded stories as I saw and heard them. Nevertheless, as detailed in the section of ethics and friendships above, I tried to ensure representations were considered fair by Embla and/or Freyja. This was not to seek any truth or objectivity, but in order to treat stories, and participants, with the respect they deserved.

Approach to analysis

The above outlines some of the physical practices I employed to organise data. As is the case with ethnographic research, analysis was happening from day one (Charmaz, 2000; Tedlock, 2000). I used my research diary to both generate and analyse data (Richardson, 1998). Similarly to Wickenden’s (2010, 98) research, my analysis was very much “an iterative and inductive process, where issues gradually emerged from what the young people did and told me and my reflections on this.” Claiming I took an inductive

approach to research, however, is not to say I was not influenced by “a desire to see certain phenomena” (Goodley, 1999, 33). As I argued earlier, my research grows out of my discontent at the unjust treatment of young and disabled people in neoliberal Britain. It attempts to tap into the “creative imaginings” of young disabled people, to think-through “how things might be better” (Sargisson, 2000, 3). If *Section One* was about me queer(y)ing, *Section Two* is about young disabled people crippling the world around us. In a review of McRuer’s *Crip Theory* (2006), Bennett (2007) writes that crip theory is “on the edge of queer and crip activism and social movements”. It is a statement I would be pleased to associate with my work with. I have made clear from the outset of my thesis that something feels very self-indulgent about doing a PhD, especially at a time when my friends and family are struggling to find work. Bridging my research with activism; listening to and taking seriously the ideas of young disabled people who are so often denied this, allows for some personal justification. I entered research, and therefore analysis, with an agenda.

According to Goodley and Lawthom (2005), in order to assess research around disability researchers are commonly asked about the analytical levels their work seeks out: “does research investigate politics, culture, society, relationships or the individual”? (cited in Goodley, 2011, 23). As I outlined above, *The Best-Ever Future Worlds Project* allowed me to move discussion from individual youth-adult transitions we are often presented with (see *Chapter Two*), to instead talk to young disabled people about their relationships to and with politics, culture and society. In employing the range of methods I outlined above I wanted to listen carefully to, try to understand and take seriously young disabled people’s actions, thoughts and feelings (Biklen, 2004). Analysis involved taking the stories and ideas of young disabled people and reflecting back over *Section One* to consider how and if data related to my earlier theorisations around youth and disability. In doing this analysis began to emerge on a number of levels.

Analytical Level	Description	Example of data (and where used in analysis)	Data Collection
Subjective	Stories individuals told me about themselves. Personal hopes and dreams for their individual futures.	Pause looks forward to a time she has the money and freedom to go to a nightclub (<i>Chapter Six</i>).	Recorded interviews. Conversations recorded in research diary (all fieldwork contexts). ‘Reports from the Future’ (Explore).

Relational	How young disabled people related to, were treated by and resisted the treatment of others around them. Included looking at networks of support and interdependence.	Relationships with PAs in Iceland (<i>Chapter Seven</i>) Sooboo’s negotiations of the disablist attitudes which threaten to stifle his artwork in <i>Explore (Chapter Six)</i> .	Recorded interviews. Conversations recorded in research diary (all fieldwork contexts). Group discussions (futures workshops, YF). Observations recorded in research diary (<i>Explore</i>).
Economic and material	How economic structures impact on young disabled people’s lives: both in terms of being a producer (finding work) and a consumer (access to the markets). Physical barriers in the lives of young disabled people.	Young people in first futures workshops at YF write of postcard to stay in the past: ‘ <i>disabled people getting a bad deal with jobs (because of bad attitudes)</i> ’ (<i>Chapter Seven</i>).	Group discussions (futures workshops, YF). Photos (cameras workshop, YF). Interviews (Colin). Stories recorded in research diary (Iceland).
Cultural	How normative representations of disability, youth, adulthood, and other intersecting identities (gender, sexuality, race, and so on) impact upon young disabled people.	Julia in <i>Breaking through Limitations</i> remarks “people don’t want to see a pregnant disabled woman” (<i>Chapter Eight</i>).	Individual stories told, conversations had, and interviews recorded (all fieldwork contexts). Discussions arising from ‘ <i>Reports from the Future</i> ’ (<i>Explore</i>). Observations (<i>Explore</i>). Groups discussions (futures workshops, YF). Discussions (<i>Breaking through Limitations</i> , Iceland).

Figure 15 Levels of analysis

As analysis was happening from the beginning of research (Charmaz, 2000; Tedlock, 2000) the above analytical levels began to emerge before I went to Iceland. However, spending time with young disabled people, especially to the extent I did in Iceland, made

me realise more than ever that as a non-disabled researcher I knew nothing about the levels of disablement in the lives of disabled youth (Goodley, 1999). I explain further in *Chapter Seven* that in the early stages of analysis I worried my queer(y)ing of adulthood in *Section One* was oppositional to some of the messages I was getting from young disabled people, striving to be included in normative discourse. Crip theory, according to Bennett (2007), is to CDS what queer theory is to LGBT politics. As explained in *Chapter Two*, queer theory developed as a 'binary breaker', questioning the boxing in of 'non-normative' sexuality. CDS similarly questions binaries, disabled/non-disabled being one example. Both queer and crip, therefore, require an intersectional approach to activism and academia. My work undoubtedly wanders, borrowing from other disciplines, and sometimes appearing to leave 'youth' and 'disability' to one-side in order to pursue a tangent. Yet, spending time with young disabled people brought me back down to earth; this wandering, leaving disability behind, was not so possible when you were stuck at home without assistance, or denied access to your friend's gig (a story of Colin's which I share in *Chapter Seven*). As Hughes et. al (2005, 14) put it: "[t]he 'travellings' and the liquid identities of people who live a 'de-territorialised', nomadic life (Deleuze & Guattari, 1986) will seem strange to disabled people with mobility and some sensory and communication impairments." Identity political fights were part of the lives of those in YF and Iceland. It was important, therefore, to remember my partisanship: beginning "firmly on the side of disabled people" (Goodley and Moore, 2000, 826). "Qualitative methods are impressionistic and unsystematic. [...] Researchers may only see what they want to see" (Goodley, 2000, 64). Therefore, I validated my ideas with young disabled people throughout the continuous and iterative process of analysis (Zarb, 1992). Embla and Freyja were my main points of call to try ensure my analysis resonated with my young disabled participants.

I took with me to Iceland a whole host of ideas and analytical points that had arisen from UK data. I talked these through with Embla and Freyja. As argued above, my data, especially within my research diary, is unashamedly a narrative construction, formed by me, about my engagement with young disabled people (Charmaz, 2000; Denzin, 1998). As young women engaged in both CDS and identity political fights, however, Embla and Freyja helped me to understand the strategic importance of employing different arguments at different times: sometimes arguing one's place within normative discourse, whilst in more critical arenas (and when it was safe to do so), questioning the very discourse you were previously fighting to be part of (an argument I make throughout

analysis). Representing your friends, analysing their stories, and holding them up for public scrutiny is a daunting task, but one, on reflection, it was important for me to encounter. As Embla and Freyja (and also, perhaps Colin) would likely be present at, read, or hear later about ways in which I had presented their stories, I was careful to remain as close to the stories of participants as possible. With Embla and Freyja, I could not hide behind academic jargon and alienate them from their stories.

Answering research questions through and with the lives of young disabled people

“Two of the main purposes of disability research are first, to unmask the processes of disablement and, second, to pinpoint how resilience is borne out of these exclusionary environments” (Goodley, 1999, 41). From my utopian project, I hoped to find out a) what was wrong with the world in the eyes of young disabled people; and b) how things could function otherwise. This worked in line with my research questions.

Research question one

Research question one asks what dangers young disabled people face if normative discourse remains unquestioned. To answer this question, my analysis sought out “processes of disablement” (Goodley, 1999, 41): how are young disabled people excluded from discourses of youth and adulthood, and what are the potentially dangerous consequences of this? I have begun to consider this question over *Section One*. In *Chapter Two*, we saw the dangers of disposability facing young disabled people who do not conform to normative discourses of becoming independent and economically productive adults (Giroux, 2009). *Chapter Three* took the strange and gendered concept of adult-youthfulness to argue that normative and idealised images of women’s bodies do little for the well-being of young disabled women. A utopian project was useful as asking disabled youth about their utopian future visions demanded a simultaneous critique of the here-and-now (Geoghegan, 1987; Gordon & Hollinger, 2002; Little, 2006; Sargisson, 2000). Critiques of the here-and-now alerted me to the dangers of not questioning normative discourse. This was recorded in the following ways:

1. Ethnographic field notes collected during time at Explore.
2. Photographs taken at cameras workshop at YF.
3. Annoyances written onto postcards used in the bin/ time travelling post-box activity at YF.

4. Subsequent discussions caught on recording of YF futures workshops.
5. Interviews with Colin.
6. Discussions of the above with Embla and Freyja, leading to further stories from their own lives.
7. Other stories Embla and Freyja shared, both with me specifically, amongst groups of friends, and at public conferences.

Chapter Six considers the consequences of passivity for disabled youth in segregated leisure schemes. *Chapter Seven* considers the dangers young disabled people face when we do not question a discourse of youth as becoming-independent-adult. *Chapter Eight* concentrates on the dangers of positioning disabled youth as genderless and asexual.

Research question two

Research question two asks how disability researchers can share the stories of young disabled people in order to reposition them as active and politically resilient. To address this question I want to know “how resilience is borne out of [...] exclusionary environments” (Goodley, 1999, 41); stories of disabled Youth as Active.

Bennett (2007) writes that crip theory is “concerned with the ways in which neoliberal capitalism (the dominant economic and cultural system as driven by market priorities) has imagined and composed sexual and embodied identities.” I continually highlight that a focus on neoliberal productivity (a very specific form of productivity associated with fitting into capitalist systems) creates an expectation on young people to conform to a particular notion of adulthood. With these narrow definitions of adulthood, come similarly restricted conceptions of valued activity (*Chapter Two*). With participants in Iceland and at YF political engagement was explicit. Their stories shared in *Chapters Seven* and *Eight* showcase this. Young people in Explore, however, had no explicit political affiliations, yet, as utopian thinking is inherently political (Sargisson, 2000), *The Best-Ever Future Worlds Project* allowed me to highlight young disabled people’s political engagement nonetheless. Thus, countering the linking of disability and passivity. In *Chapter Six* I draw upon youth subcultural studies to seek out cultural moments of conflict and struggle (McRobbie, 2000) within Explore to highlight these young people’s active resilience to disablist structures.

Research questions three and four

Research questions three and four ask what disability and the lived-experiences of young disabled people can teach us about youth, and what youth and the lived-experiences of young disabled people can teach us about disability. I wanted to know how the world could function otherwise. How were young disabled people crippling discourses of youth and disability; and how could this help us think about more inclusive ways of becoming-in-the-world-together (Shildrick, 2009)? Again, my theorising over *Section One* began to address these questions. In *Chapter One* we saw the ableism inherent to normative discourses of adulthood, and therefore disability taught us about the exclusionary nature considering youth as becoming-adult. *Chapter Three*'s feminist-disability analysis added theoretical depth and complexity to an analysis of idealised bodies we equate with 'youthfulness' (Garland Thomson, 2002; Heiss, 2011); therefore, disability taught us about the gendered nature of youthful bodies. In *Chapter Four* I argued that thinking about youth and disability, alongside queer, postcolonial and Deleuzoguattarian theories can help us to see the potential of considering youth, not as becoming-adult, but an overt time of becoming-in-the-world-together (Shildrick, 2009). Disability and youth work together to reveal each other's productive potential.

Young disabled people were striving to be accepted in discourses of youth as becoming-adult. I saw this in the following contexts:

1. The bin/time-travelling post box activity in the YF futures workshops (and simultaneous discussion as the session was recorded).
2. Interviews with Colin.
3. When learning about IL philosophies in Iceland.
4. In strives Embla and Freyja took to be recognised as gendered and sexual beings; never missing an opportunity to get dressed up when going downtown, for example.

The above were all identity political battles that challenged dominant discourses of disability. Thus disabled youth teach us about alternative ways to think about disability, answering research question four. Yet I also argue, in *Chapters Seven* and *Eight*, that by challenging dominant conceptions of disability, young disabled people were simultaneously reconceptualising what it means to be adult (or, youth as becoming-adult).

The analysis in *Chapter Six* draws on data from the YF cameras workshop and Explore. Although not talking to me through a disability narrative, young disabled people in Explore did assert themselves as youth. I used this data to ask what young disabled people can teach us about the here-and-now experiences of being young.

Discussion

This chapter has outlined my methodological influences, how these affected the methods over the three contexts of my research, some of the ethical dilemmas I have faced along the way, and finally how I have approached analysis. As sketched out above, over the next three chapters I go on to answer my research questions through and with the lives of young disabled participants. I do this through a crippling analysis; using the axis of disability, traditionally construed as Other, to turn a gaze back on what too often goes unquestioned. Disabled youth help us to re-think implicit notions around ‘youth’ and ‘adulthood’ in ways that can be beneficial for more than just disabled young people. My methodological aim in this chapter was to develop a crip methodology; a methodology which uses disability to highlight, critique and counter normative expectation.

Researchers from within the sociology of childhood have argued that emerging methods developed for use with children are also useful when researching with adults (Best, 2007). I argue that my methodology is not specifically for research with/on/about disabled youth, but a methodology for imagining otherwise which respects, draws on and positions itself with queer, critically young and crip frameworks. This is a methodology attempting to illuminate, consciously working against, and seeking alternatives to normative expectation, whatever axis (gender, sexuality, race, age, dis/ability) it emerges against. I turn now to the ideas generated through this method/ology by continuing into *Section Two: Reconstruction, Transformation*.

Chapter Six

Disabled Youth as Active; Questioning Youth Culture

Introduction

“Access – it sometimes seems as though some people have it and some don’t. But what if access is much more than such an individual state of affairs? What if access is much more than a substantial, measurable entity? What if it is more like a way of judging or a way of perceiving?”

(Titchkosky, 2011, 3)

CDS scholars note that young disabled people are denied access to ‘youth cultures’ that are open to their non-disabled peers (Hughes, et al., 2005; Priestley, 2003). *Chapter Six* begins with this assertion. I first use data from the camera’s workshop with YF (outlined in *Chapter Five*) to agree that disabled youth face barriers which exclude them from the same pursuits as their non-disabled peers. Titchkosky (2011, 27) writes, however, that “[h]alf of the battle is the fight for access the other half is the need to think about or question what we have indeed been given access to.” Prompted by Titchkosky (2011) I use this chapter to critically engage with the meanings commonly attributed to ‘youth culture’ through the sharing of stories from young people involved in art group, Explore.

I explore ‘youth culture’ by engaging with youth subcultural studies. Feminist youth subcultural researchers have highlighted the discipline’s male-centric tendencies (McRobbie & Garber, 2000). I further note the lack of engagement between youth subcultural and CDS researchers. Drawing on feminist subcultural work I argue that as well as sexism, youth culture smacks of ableism. I wonder whether this is why disabled youth do “not yet figure as a necessary participants” (Titchkosky, 2011, 16) within youth culture. Feminist youth cultural researchers have argued the importance of incorporating the experiences of young women into youth subcultural studies. I show young people in Explore asserting themselves as youth. Considering definitions of ‘the cultural’, I argue that disabled youth *are* involved in youth cultural negotiations. Therefore we should use disabled youth’s cultural engagement to expand notions of youth culture. Thus, I address

research question three as I wonder what disability and the lived-experiences of young disabled people teach us about youth.

I therefore turn to consider the common assertion that youth culture depends upon adult-free arenas (Hughes et al., 2005). Whilst not denying young disabled people's right to spend time apart from an adult-gaze, I wonder how useful this conception is to disabled youth. I thus consider the relationships between my young disabled participants and their parents. These relationships lead me to question disabled/non-disabled, youth/adult and child/parent binaries. Arguing that dominant notions of 'youth culture' are unrepresentative of many young people's lives (Bennett, 2008), I argue that breaking down such binaries can help us to develop hybrid spaces, in which we can together be critically young.

I begin, however, by first considering initial concerns posed by those at the Youth Forum (YF) which have prompted this chapter: the inaccessibility of places young people may wish to spend time. Or, access as a thing "it sometimes seems as though some people have [...] and some don't" (Titchkosky, 2011, 3).

Disabled youth's access to space

YF members began thinking-through their best-ever future ideas by considering how here-and-now annoyances could be different in the future. They wrote these on postcards to remain in the past (see *Figure 6, Chapter Five*). A conversation during this activity went as follows:

Jenny [after picking out a postcard]: Here it says that you're annoyed about the government taking away places for young people to go. What would be different in our future world?

Matthew: Government giving more people more places to go.

Margery [youth worker]: What about young disabled people? Does that include us as well?

Nathan: Yeah, it includes all of us. Us as well.

Mohammed: They need to be accessible.

Matthew: Yeah, accessible!

(Transcript from first futures workshop with YF 23rd November 2011)

YF members were frustrated about the diminishing number of places for young people, disabled and non-disabled, to spend time. They argue, however, that as young disabled

people their options are fewer, as some spaces are inaccessible to them. Priestley (2003) notes that physical barriers prevent disabled youth from accessing the same arenas as their non-disabled peers. These concerns do not only relate to formal, often government-funded services, but perhaps *especially* to casual, informal settings young people choose to spend time (Hughes, et al., 2005); such as fast food outlets (Watson et al., 1999), restaurants and pubs (Hirst & Baldwin, 1994).

That inaccessible space was a problem for some at YF became apparent in the cameras workshop (outlined in *Chapter Five* and *Appendix Six*). I asked young people to take pictures of things which annoyed them as we moved around a city centre. Below (*Figure 12*) are three examples reflecting the inaccessibility of space to young disabled people. The first shows a large silver step in front of a fast food outlet; the second captures Colin, a wheelchair user, trying to negotiate a narrow shop entrance; and in the third Colin poses, frustrated as steps are blocking his access to a pub.

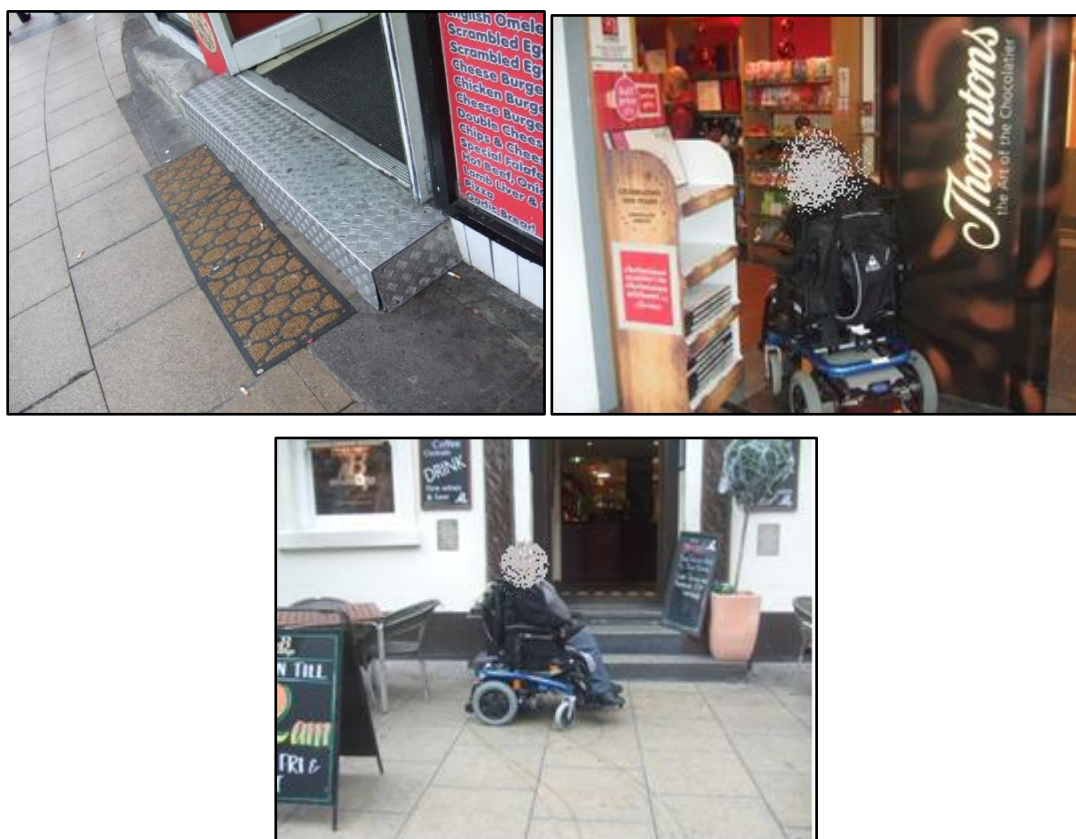


Figure 16 Photographs taken at YF capturing the physical inaccessibility of space

These pictures support Hughes et al. (2005, 11): “young disabled people, particularly those with learning difficulties or severe physical impairments will have little experience of the spontaneous, casual leisure that develops organically from peer group affiliations”.

Colin further stressed this when he told me how much forward planning is needed for him, as a wheelchair user, to spend time with his friends:

“Sonia [another member of YF] had this DJ gig in town. I really wanted to go, but I know how bad places are for me to get into, so I asked Sonia if it would be accessible. She said she wasn’t sure but she’d ring up. We both rang them up actually, and they said it’d be fine. Anyway, I get there and they’ve got her DJ-ing in the basement! There’s no way for me to get down. They gave me free drinks, but it’s not quite the same sitting upstairs on your own. £40 taxi fare that was too.”

(Interview with Colin 1st December 2011)

Colin alerts us to the daily consequences of exclusion arising from physical inaccessibility. It shows a tokenistic culture of access: the “harsh paradox of the inaccessible labelled accessible” (Titchkosky, 2011, 76-77). As Reeve (2012) highlights, even when physical access is granted, separate back-street entrances, do little for young disabled people’s self-worth. Murray’s (2002) young disabled participants stressed that spending time with their friends was more important than the particular activities they did together. Similarly, the pub apologetically offering Colin free drinks was little compensation for being excluded from his social circle.

For Colin, the £40 taxi fare adds insult to injury and highlights another plight in the lives of disabled youth: a lack of accessible public transport (Murray, 2002). Partly due to inaccessible public transport, and partly resulting from what Colin considers his parents’ over-protective attitudes (discussed further below), Colin is, at great financial cost, reliant on taxis for transport. Other pictures from the cameras workshop reflected participant’s frustration around public transport (*Figures 17-19*). Although all young people complained of barriers to accessing transport, the particular barriers faced varied (Hughes, et al., 2005; Murray, 2002). The first of photograph shows a large gap between a station platform and a train; illustrating the well-documented problem of inaccessibility of public transport to people with physical impairments (see Wilson, 2003 for an overview).



Figure 17 Photograph illustrating a physical barrier to public transport

Less widely considered, however, is the use of public transport for those with sensory and/or intellectual impairments (Lavery, Knox, & Slevin, 1997; Mathers, 2010). The picture of a speaker at a train station was taken by Ahmed, who has a hearing impairment. Ahmed complained of not being able to hear announcements. Another participant photographed a busy escalator; he said it was overwhelming and difficult to navigate when the station got busy.



Figure 18 Photographs illustrating sensory barriers to public transport

The final two pictures show the confusing organisation of timetables. Participants thought this was particularly problematic for people with intellectual impairments, but that simplifying them could benefit everyone.

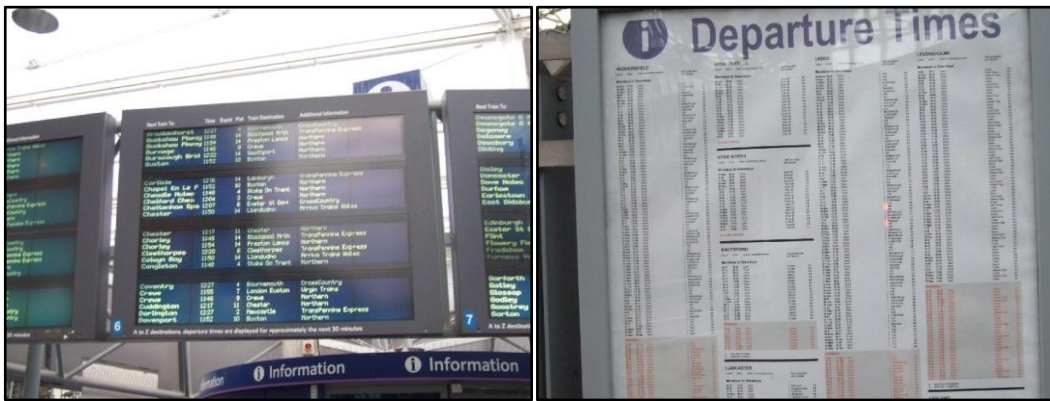


Figure 19 Photographs illustrating confusing timetabling information

These concerns resonate with complaints of adult participants with intellectual impairments (Mathers, 2010). Murray (2002) argues, however, that the accessibility of public transport may be more pertinent to disabled youth than adults, as young people are generally more reliant on public transport to get around (although she notes that not all disabled adults have the option of private vehicles). In fact, these complaints around public transport are probably feelings many of us - young, old, disabled, non-disabled - can empathise with. Stepping on the train with heavy bags in rush hour can be problematic for any number of people; not catching an announcement in a noisy station causes problems for those with and without hearing impairments; complicated timetabling has left me confused many-a-time. Access issues have come to be ‘about disability’ and concern ‘disabled people’. We forget, however, that “questions of access can arise for anyone, at any time, and anywhere for innumerable reasons” (Titchkosky, 2011, 4).

Before continuing, I stress that I do not deny that built environments prioritise certain embodiments over others; the assumed ‘able-body’. Through identity political battles disabled people have demanded, for good reason, that they should not be excluded from any aspect of life. Arguably, this is one reason access issues have come to be ‘about disability’ (Titchkosky, 2011). Yet, the continual “conflation between the radical diversity of embodiment and the single iconic figure of the wheelchair user” (Titchkosky, 2011, 81) means that access is often narrowed to simply stand for installing ramps for those who use wheelchairs (Russell, 1998; Titchkosky, 2011). This can result in tokenistic ‘access’ arrangements that prove problematic for disabled people such as Colin – you can come into the pub, but cannot access the gig. The photo below showing Colin unable to enter a bookshop despite the “iconic figure of the wheelchair user” (Titchkosky, 2011, 81), again illustrates this concern.



Figure 20 Colin unable to enter a bookshop despite the “iconic figure of the wheelchair user” (Titchkosky, 2011, 81).

I now further investigate issues of access by considering access within policy. In the UK, the *Equality Act 2010* means that disabled people using public transport “have a right to reasonable adjustments. This can include providing timetables or other information in an accessible format, where it is reasonable for the transport provider to provide it” (DirectGov, 2011b). This seems good: we have, as Russell (1998) calls for, gone ‘beyond ramps’. Yet there is a loophole: we say hello again to our friend Mr Reasonable. The demand of access must be a ‘reasonable’ one. We know from the social model that the problem is of public transport, not one of individual bodies (Oliver, 1990). Yet, Mr Reasonable’s ableist response to the question of access is to individualise: “you cannot access the train due to disability. But, as we are Reasonable People, we will meet your individual access demands, if they too are Reasonable”. Whether or not demands are deemed to be reasonable, however, in having to individually demand access, self/Other relations are sustained:

“A sense of the normal participant, not to mention normalcy itself, is achieved by imagining, discussing, and perhaps even describing the type who is outside normalcy while maintaining an illusory sense that exclusion is an act of nature and not a social act”.

(Titchkosky, 2011, 37)

As Titchkosky (2011, 77) tells us, seeking reason for demands of accessibility means that “whether or not the reasons for lack of access are judged good or bad, the social activity of people seeking reasons fosters the sensibility that lack of access is reasonable”. As a result, the bodies of those for whom transport remains inaccessible, are deemed

unreasonable; “‘naturally’ a problem for some spaces” (Titchkosky, 2011, 35). The dyad between reasonable and unreasonable bodies functions to confirm our sense of normalcy.

Titchkosky (2011, 90) asks us not just to think of access as a demand, but to use questions of access to imagine “access as a space [...] where questions of embodiment can be pursued”. We have seen that young disabled people are denied access to the same spaces as their non-disabled peers. A lack of access to public transport and the physical inaccessibility of buildings are only two ways this exclusion functions. Later in this chapter we see that Colin and Gabby from YF, for example, think medical perspectives of disability influence their parents perception of them as “more vulnerable” than their non-disabled siblings and restricts what they are able to do (Hughes, et al., 2005; Murray, 2002; Priestley, 2003). It has been recognised in literature that the practical need for physical assistance, usually provided by non-disabled adults, also prevents young disabled people accessing youth only spaces (Gibson, et al., 2012; Hughes, et al., 2005; Murray, 2002; Priestley, 2003; Wickenden, 2010).

That these concerns have been noted, fought against, yet continue to be a problem leads me to two avenues of pursuit. Firstly, we could argue the need to continue fighting for disabled youth’s access. For disabled youth, this means spelling out their continued exclusion from spaces alongside their peers. Although I maintain the importance of this, as a CDS researcher engaged in intersectional work, I want to take up Titchkosky’s (2011) gauntlet: what is this ‘youth culture’ we are arguing for young people to have access to? Noting young disabled people are refused access to youth culture, is different to the assertion that young disabled people are denied access to space alongside their non-disabled peers. I am prompted by Titchkosky (2011) to unpick the assumption that disabled youth are naturally “exclude-able types” (Titchkosky, 2003, 518) within so-imagined ‘youthful’ spaces. I need to investigate what these ‘youthful spaces’ have to come stand for, through critiquing implicit ideas around ‘youth culture’. Youth subcultural studies can help me here, so I turn to consider youth subculture studies and its relationship with disability.

Youth subcultural studies: Averse to disability?

“You can’t go clubbing or ‘hang out’ with your Mum and Dad. Youth culture depends on freedom from adult control but disabled kids – particular girls – just don’t get it (Thomas, 1998)”

(Hughes, et al., 2005, 9).

Above, Hughes et al. (2005) convey a dominant account of youth culture as risk; something young people would prefer their parents to remain unaware of. Yet, the story goes that youth culture is important to young people’s identity formation (Rattansi & Phoenix, 2005). Therefore, for CDS scholars, it is problematic that young disabled people do not have access to youth culture (Priestley, 2003). But what is this ‘youth culture’ we worry young disabled people do not have access to? What makes it a risky yet ‘character building’ activity? If we begin to understand what youth culture is and stands for, we may be able to work out why young disabled people figure as “exclude-able types” (Titchkosky, 2003, 518) within it.

Let us begin with the assumption that youth culture depends on adult-free space. Out of all my participants, the worries about lack of access to adult-free arenas and therefore ‘youth culture’ are arguably most applicable to those at Explore. In the other two research contexts, with YF and in Iceland, participants were explicitly involved disability politics. Members of Explore, on the other hand, rarely spoke to me about disability (in a political sense, or otherwise). Explore is an art group funded by the government initiative, *Aiming High for Disabled Children*. Explore is run for, rather than by, disabled people. Out of all strands of my research, it is most typical of the kinds of segregated schemes Hughes et al. (2005) argue separate disabled youth from their non-disabled peers. Furthermore, Explore is specifically for those with labels of intellectual impairment, whom it has been argued have less access to youth only spaces than those with physical impairments (Murray, 2002). The young people in Explore therefore have the most to teach me about the exclusionary nature of youth culture (Shildrick, 2003).

Fieldwork with Explore started shortly after the beginning of a new academic year. For 16-year-old Pause, that September meant moving from her previous segregated school to study ICT at a mainstream college. She was enjoying the additional freedom this allowed her: travelling to and from college (and Explore) by bus; lying-in when she had a late start; and finding college staff had more relaxed attitudes. Like the rest of the group, I

asked Pause to begin by filling in the ‘*Report from the Future*’ (*Appendix One*). The second question in the booklet asked Pause the age of her time-travelling avatar. I stressed that this did not have to reflect young people’s real age. Pause chose 21. Interviewing Pause later, it seemed 21 represented a time when she would spend more time in places she considers for young people:

Jenny: How old’s your time traveller?

Pause: 21

Jenny: Any reason you went for 21?

Pause: It’s just a good age. I’d like to be 21.

Jenny: How come?

Pause: Because you’re still young but you have more freedom.

Jenny: What would you do if you had more freedom when you were 21 that you can’t do now?

Pause: I’d have more money and I’d go to nightclubs. [Pause turns, attempting to catch the eye of one of the older staff members, and raises her voice] ...because they’re not for old people.

(Interview with Pause, 12th October 2012)

Pause wants both the finances and freedom to go clubbing, as nightclubs are spaces she deems “not for old people”. Hughes et al. (2005, 9) and Pause are in agreement: “You can’t go clubbing or ‘hang out’ with your Mum and Dad.” I now consider this further through engagement with youth subcultural studies.

Club scenes are one example of a cultural space youth subcultural researchers have considered ‘youthful’ (McRobbie, 1993). Since the post-war years the identity-forming time of youth has been defined through production and consumption: of music, fashion, film and so on (France, 2007; Hughes, et al., 2005; Rattansi & Phoenix, 2005). Particularly during the 1990s clubs were considered one area of consumption (McRobbie, 1993). Conceptualising ‘the cultural’ was key to the projects of youth subcultural researchers. According to the *Oxford Dictionary of Sociology* (Scott & Marshall, 2009, 152), “in social science, culture is all that in human society which is socially rather than biologically transmitted, whereas the common-sense usage tends to point only to the arts. Culture is thus a general term for the symbolic and learned aspects of human society.” As explained in *Chapter One*, youth subcultural studies emerged as post-war years saw vast social and political changes, which, it was argued, resulted in the category of youth (Clarke, Hall, Jefferson, & Roberts, 2006). For the first time young people were in possession of a disposable income. This, combined with supposedly diminished responsibilities compared with their adult counterparts, resulted in youth

markets (Hodkinson, 2008) and hence the rise of certain ‘youth subcultures’ (teddy boys, mods, rockers, and so on). The influx of subcultures brought ‘moral panic’ (France, 2007) which positioned young people paradoxically. Young people were deemed passive in accepting the social “learned aspects of human society” (Scott & Marshall, 2009, 152) offered by the markets. However, the ‘deviant behaviour’ displayed through subcultural activity was seen as a dangerously *overactive* response to market appropriation. Youth subcultural research aimed to challenge this.

Youth subcultural researchers connected lived subcultural experiences to broader cultural and social structures, arguing that the relationship between young people and youth consumer markets was dialectic (Clarke, et al., 2006). Willis (1977, 4) explains this when he defines his youth subcultural studies perspective on culture as “not simply a set of transferred internal structures (as in the usual notions of socialisation) nor as the passive result of the action of dominant ideology downwards (as in certain kinds of Marxism), but at least in part as the product of collective human praxis”. For youth subcultural theorists, one does not passively become part of a particular culture, but continually (re)establishes and (re)asserts a presence within it, which simultaneously affects the cultural group itself. It was important for youth subcultural researchers to conceive ‘the cultural’ as dialectic to shift notions of young people as passive pawns (as previous modernist research had made them out to be – see *Chapter One*) to active agents. For this reason, youth subcultural researchers have been praised for offering rare positive accounts of, what I have called, Youth as Active.

It has been argued that conceptualising youth culture as ‘subcultural’ is unsuitable for a postmodern age (Muggleton & Weinzierl, 2003). Yet we continue to see consumption as key to the identity formation of young people (Hughes, et al., 2005). *Chapter Two* argued that young people’s activity is only praised if it is defined in relation to economic spending power. As Davis (2002, 27) puts it: “the contemporary body can only be completed by means of consumption”. For my project, the strength of consumption has become particularly clear when considering the construct of Youth for Sale (*Chapter Three*). I engage further with consumption in respect to becoming-independent in *Chapter Seven* and Youth for Sale in *Chapter Eight*. In this chapter, however, a focus on consumption alerts us to another barrier young disabled people face when wishing to access places with their non-disabled peers: finance (Hughes, et al., 2005; Priestley, 2003). Disabled people and their families are more likely to live in poverty than families

without a disabled member (Every Disabled Child Matters, 2007, 2011a; Sharma, 2002). We have seen the potentially higher costs related to being a disabled young person, when we consider for example, Colin having to travel in taxis rather than buses. When Pause looks forward to a time she has more money, granting her access to nightclubs, it seems she is conscious of financial barriers. We also know, however, that consumption is not only materially but also *discursively* problematic to disabled youth. In *Chapter Eight I* highlight how young disabled people felt excluded from the ‘sexy signifiers’ of Youth for Sale (Hughes, et al., 2005). If ‘youth culture’ relies upon constructs of Youth for Sale, we begin to see how youth cultures make disabled young people, relegated to the realms of Youth as Passive, appear as “exclude-able types” (Titchkosky, 2003, 518); out of line with dominant conceptions of youth culture (Hughes, et al., 2005).

In the late 1970s and early 1980s criticisms emerged that researchers were focusing exclusively on public displays of white, male youth (Dorn & South, 1999; McRobbie, 1980, 1990, 2000; Rattansi & Phoenix, 2005). Rattansi and Phoenix (2005) highlight that minority ethnic identities were only taken into account as influential or oppositional to predominately white subcultures, and Hall and Jefferson (2006a) note a missing critique of sexuality. In the main, however, critics focus upon the exclusion of young women (Hall & Jefferson, 2006a; McRobbie, 1980, 1990; Rattansi & Phoenix, 2005). Yet disability is rarely mentioned (Baron, Riddell, & Wilson, 1999; Butler, 1998). Scholars such as McRobbie (1982) argued that by focusing only on overtly public displays of young men, researchers were excluding the more mundane, albeit just as real identity forming experiences happening behind closed doors (see also, Dorn & South, 1999; McRobbie, 1980, 2000; Rattansi & Phoenix, 2005). If we consider the situation of disabled young people, often constricted to private spheres (Hughes, et al., 2005), disability becomes conspicuous by its absence. This in itself could tell us something. It could tell us that disabled youth were excluded from youth subcultures per se. We could look historically to consider the position of disabled youth at the time of the youth subcultural heydays (1960s and 70s) to support this argument. Yet, we could also consider this more critically. Those with visible physical impairments may not have been present, but what about those with hidden and/or intellectual impairments? Do silences tell us as much about the perspectives of the researchers themselves, that disability was not part of the agenda, as it does about disabled young people’s subcultural engagement? McRobbie and Garber (2000) highlight that youth subcultural researchers were drawing on what were new theories of deviance, which considered so-called deviant activity

within wider societal and cultural practices. They argue that, with the possible exception of sexual deviance, girls and women were not considered excitingly deviant *enough* to be celebrated within these frameworks: could we say the same for disabled youth, with its connotations of paternalism and passivity?

I consider this further by introducing another story from time spent with Explore, and thinking this through alongside Willis' (1977), '*Learning to Labour*'. Willis (1977) engages with a group of lads in a secondary modern school. Willis' lads had little motivation for the formal lessons of the school, bragging about their avoidance of work. However, their main aim was not to physically remove themselves from the school. There was little need, as they had other ways of ensuring their days were self-directed. The school used on their own terms was an interesting place to 'be with the lads'. Willis shows that the lads' defiance to conform to school timeframes meant they were written-off early by staff and other students. Rather than considering the school system as unmeaningful to these students' social and cultural positions, those around the lads considered them as annoyances; dangerous and disruptive Youth as Active. What, though, if Willis' lads had not been working-class white young men, but disabled young people refusing to conform to normative rules, structures and timeframes? How would they have been thought of by teachers and other students then? I recorded the following in my research diary, after meeting 13-year-old Sooboo:

"Sooboo's has a strong Islamic faith. He makes the most out of Explore: using it to pursue his personal interests in languages and dentistry (the latter being one of his career aspirations). He regularly breaks away from his art to teach others the Arabic alphabet, or to squeeze remnants of high-school language lessons from members of staff. Another way Sooboo furthers his interest in languages is to watch cartoons in a variety of languages on YouTube; ensuring he has time at the end of sessions to use Explore's computers. When Gareth's Mum, a doctor, arrives, Sooboo fires questions at her about teeth."

(Research diary, 12th October 2011, first Explore session)

Willis (1977) argues that the lads' rejection of the school was not without purpose. Rather, it was "an aspect of [the lads'] immediate identity and self-direction. Time is used for the preservation of a state – being with 'the lads' – not for the achievement of a goal – qualifications" (29). Above Sooboo displays his own strategies of claiming back time from the (semi)formal structure imposed by Explore and myself, in favour of his own here-and-now priorities, interests and learning. This philosophy to education was reflected in a piece of artwork Sooboo created called 'a future day in the life of Sooboo'

(*Appendix Fifteen*). In this artwork we see that, given the free reign to do as he liked, Sooboo would study languages in the morning, and in the afternoon learn about time and camera light. This learning would not take place in school. Spanish would be taught in Spain, by a Spanish woman who (as Sooboo put it in an interview) “does not speak Arabic, Hebrew, English, French or Dutch, but only Spanish”. Sooboo’s days of learning would be punctuated with activities he enjoyed: going to soft play, mosque and feeding chickens. Learning tailored to suit his interests, taking place at times satisfying him. Furthermore, it is a philosophy to education which Sooboo employs during Explore. Yet, like Willis’ (1977) lads, when Sooboo refuses imposed structures and timeframes, instead adopting his own philosophy to education, he is not praised for his desire to teach and learn, but conceived as a problem. However, rather than a rebellious, dangerous and disruptive Youth as Active problem like Willis’ (1997) lads, Sooboo’s refusal to conform is read as a disability problem. This disability problem renders Sooboo the decidedly less exciting and glamorous, Youth as Passive. After my second session with Explore Sooboo’s story continues:

“Sooboo was telling me about sharks’ teeth today. It was cool. I got quite into the discussion, only momentarily finding it weird that [member of staff] kept changing the subject. I figured she just wasn’t interested. Later she pulled me to one-side, and told me not to talk to Sooboo about teeth, apparently an instruction passed on from his mother, on the advice of his school.”

(Research diary, 19th October 2011, second Explore session)

It is not that young disabled people lack agency, argue Hughes et al. (2005, 7), but that formal, segregated leisure schemes create ‘docile subjects’. Disallowing Sooboo to talk about teeth is an attempt to render him docile. It is, I would argue, an act of what Deal (2007) terms, ‘aversive disablism’: subtle prejudice which, although harmful, is often carried out unintentionally, perhaps even with good intentions. Explore staff, the teacher and Sooboo’s mother were all acting on the advice of those positioned as ‘expert professionals’. As Freyja put it at a conference around independent living (discussed further in *Chapter Seven*), it exemplifies an “it’s for your own good attitude [that] disabled people face on a daily basis”.

To consider Sooboo’s situation further I introduce more CDS literature. I also (begrudgingly) share with you Sooboo’s diagnosis of autism. In their paper ‘*Reading Rosie*’, Goodley and Runswick-Cole (2012b, 56) introduce us to 11-year-old Rosie, who also has a diagnosis of autism. They write accounts of Rosie’s life through four different

lenses: 1) the ‘autism canon’; 2) a social model perspective; 3) the Nordic relational model of disability; and 4) a socio-cultural lens. Sadly, it is the ‘autism canon’ which resonates most closely with the particular positioning Sooboo is given in *Explore*. ‘Reading Rosie’ through the ‘autism canon’ Goodley and Runswick-Cole write:

“As well as obsessing about Kitty, her new toy, [Rosie] also shows an obsessive interest in Goodies DVDs and Greek myths. Rosie has an impressive knowledge of vocabulary on the topic of Greek myths, however, this seemingly developed area of competence is a product of her fascination with mythology and should not distract from an understanding of the devastating impact of autism and learning difficulty on her life.”

(Goodley & Runswick-Cole, 2012b, 60)

Rather than logical conclusion of his ambition to become a dentist, the autism canon makes Sooboo’s interest in teeth an obsession; a ‘symptom’ of his impairment label which it is desirable to solve. The solution is to render Sooboo docile by refusing to acknowledge talk about teeth, arguably with the intention of guiding him to normative adulthood (Goodley & Runswick-Cole, 2010). Sooboo is approached and attempts are made to root him as Youth as Passive.

After they have ‘read Rosie’, Goodley and Runswick-Cole (2012b, 63) write that they “see Rosie as a postmodern child, a child of which many stories can be told”. They ask us to consider our own readings and writings of disabled children. When youth subcultural researchers argue that young people are not passively appropriated by markets, but actively engaged within and shaping them (Hall & Jefferson, 2006a; McRobbie, 2005) they attempt to tell different stories about young people. When Willis (1977, 29) highlights the purpose of the lads non-conformist attitudes was “an aspect of [the lads’] immediate identity and self-direction”, he is telling a different story to the one imagined by the teachers and other students. Telling different stories is one of the aims of my thesis, as outlined by research question two: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient? I use Sooboo’s story to highlight the different ways people are conceptualised as problems, dependent upon identity. The problem of Willis’ (1977) non-conformist white, male working-class youth = Youth as Active. The problem of Sooboo, a non-conformist disabled youth = Youth as Passive. If we consider young disabled people’s positioning as passive youth, perhaps it is unsurprising that disability was not on the cards of youth subcultural researchers (Baron, Riddell, et al., 1999; Butler, 1998).

If we continue with Sooboo's story, however, we see that "disabled people are not simply passive victims of [...] disablism - many exercise agency and resist" (Reeve, 2002, 493).

As fieldwork with Explore continued, not being able to talk to Sooboo about teeth became more ridiculous. Sooboo was sure from day one that a dentist would be the main feature of his final art piece, yet staff kept referring to it as 'the building'. In my penultimate session with Explore I recorded the following:

"Hurrah! Today I witnessed a momentous event! Whilst staff were distracted, Sooboo sneakily constructed a dentist sign which is now stuck proudly on his DENTIST (not building!) in his ideal world!"

(Research diary, 7th December 2011, Explore ninth session)



Figure 21 The dentist in Sooboo's final art piece

Sooboo wins out!! Or... have I gone too far in my celebrations? Is Sooboo's dental sign a signal for celebration when we consider all the confusing, contradictory, oppressive, constricting and exclusionary messages delivered around youth and disability? Like the debates roused by both queer and CDS (see *Chapter Four*) some argue that youth subcultural researchers allowed for too much agency: ignoring regulation, constraint, and the perpetuation of injustices, thus, "adumbrat[ing] the need for complex understanding of power by suggesting it can be too easily opposed, countered or thrown off by so-called active agents" (McRobbie, 2005, 86). My celebration of Sooboo's dental sign could be

illustrative of this. After all, through the camera lenses of young people at YF and the words of Pause at the beginning of this chapter, we saw some of the barriers young disabled people face in accessing ‘youthful spaces’.

I take note from Goodley (1999, 41, my emphasis), however, when he writes, “two of the main purposes of disability research are first, to unmask the processes of disablement, and second, to pinpoint how resilience is borne out of these exclusionary environments ... experts of disablement [such as Sooboo] can alert us to the characteristics of disabling environments *and* point us to the origins of resilience”. Therefore, whilst not denying disabled youth’s right to access the same spaces as their non-disabled peers, in light of the above discussion I wonder whether rather than assume young disabled people are not a part of youth culture (hence rendering them passive), it would be more useful to question the meanings we attribute to both disability and youth culture. Hence, pondering research questions three and four: what disability and the lived-experiences of young disabled people can teach us about youth; and what youth and the lived-experiences of young disabled people can teach us about disability. We have seen throughout my thesis the complicated ways ‘youth’ is discursively constructed, and the equally complex ways disabled people are rooted through discourses of disability. To speak unquestionably of a ‘youth culture’ is to deny the multiplicity of ways young people ‘do’ ‘being young’; hence further distancing young disabled people from discourses of youth. Perhaps adding to discourses that make young disabled people appear reasonably excludable (Titchkosky, 2003) from spaces accessible to their non-disabled peers. I turn now to call on some of the later feminist subcultural texts to help me think-through how disabled young people ‘do youth’, and what this can teach us about conceptions of youth culture.

Feminist critiques of youth culture and disabled young people ‘doing youth’

McRobbie and Garber (2000, 13) highlight that class was the pivotal concern for the study of male subcultures. Class was then used to consider school, work, leisure and the family (with least emphasis on the latter); social context; and post-war structural changes that define male subcultures. They argue the importance of feminist subcultural work adding questions of sex and gender to discussions of youth culture, asking questions such as:

“Are they [girls] present but invisible [in ‘youth subcultures’]?”

Where present and visible, are their roles the same, but more marginal than boys’, or are they quite different?

Is the position of girls specific to the subcultural option, or do their roles reflect the more general subordination of women in the mainstream culture?

If subcultural options are not readily available to girls, what are the different but complementary ways in which girls organise their cultural life?

Are these, in their own terms, subcultural?”

(McRobbie & Garber, 2000, 14)

McRobbie (1980) addresses the first three questions by reconsidering ‘classic’ subcultural texts from a feminist perspective. She asks what the silences around young women and girls tell us about gender relations. As a CDS youth researcher, I could similarly ask what the silences around disability teach us about dis/ableism within subcultures. Yet, I argue to address this in terms of young women is easier than from the perspective of disability. Although accounts of women are peripheral and often derogatory, harking to the sexism apparent in male youth subcultures (McRobbie, 1980; McRobbie & Garber, 2000), women and girls are, unlike disabled young people, mentioned within texts (Butler, 1998). I assert again, although I do not deny structural and attitudinal barriers young disabled people face in accessing youth-only spaces (Priestley, 2003), I do not want to assume a lack of youth subcultural engagement with disability necessitates a lack of young disabled people’s involvement in ‘youth culture’. I am therefore interested in the latter of McRobbie and Garber’s (2000) questions. I concur with the authors that ‘subculture’ has acquired “strong masculine overtones” (14), which may render girls’ subcultures invisible. I add that ‘subculture’ also smacks of ableist overtones: youth subcultures associated with freedom, speed, and vitality, quick and spontaneous sex (Hughes, et al., 2005).

McRobbie (2000, 45) writes “only by working away from the more transparent or mainstream youth and in [her] case working class female youth, is it possible to piece together and understand girl’s culture”. Although members of Explore (unlike in other research contexts) did not talk to me about being *disabled* people, they did assert themselves as *youth*. Considering the way young people ‘did’ ‘being young people’ can help us “work away from more transparent or mainstream youth” (McRobbie, 2000, 45). However, whereas McRobbie tries to “*piece together* and *understand* girls culture” (McRobbie, 2000, 45, my emphasis), I instead consider the ways young disabled people negotiate ‘youth’ in order to *pull apart* and help us *expand* notions of youth culture. Thus

I address research question three by wondering what can disability and the lived-experiences of young disabled people teach us about youth, and help us reconceptualise youth culture in ways that would be inclusive to a multiplicity of dis/abled young people. I come back to this later in the chapter, for now though, I concentrate on research question two: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient? I draw on feminist youth subcultural texts to help me in this task.

We saw earlier Pause asserting herself as youth as she declared that nightclubs were “not for old people”. Pause specifies that nightclubs, along with funfairs and shopping centres are places she would like to spend time. Although Pause’s barriers to accessing these spaces may not spring to mind under the “single iconic figure of the wheelchair user” (Titchkosky, 2011, 81), I have discussed the attitudinal, financial and informational barriers she may face in accessing these spaces as a young woman labelled with intellectual impairments (Murray, 2002). However, like the young disabled people in Murray’s (2002) study, Pause emphasised that it was more important for her to generally ‘hang out’ with friends than take part in any particular activity. Although Pause spoke seriously of wanting to work with children when older, she was aware that in the current political climate it was particularly difficult to get a job. This would not be a problem in her ideal world, in response to the question, “How does the future person spend their day? Do they have a job? Go to school?” Pause writes, “They do not go to school or have a job. They just relax” (*Figure 22*). I asked Pause to expand:

[Jenny]: What do they do if they don’t go to school or have a job?

[Pause]: You know, just relax. Be lazy. You don’t always have to be doing something – what about just doing nothing with your mates.”

(Interview with Pause, 10th October 2011)

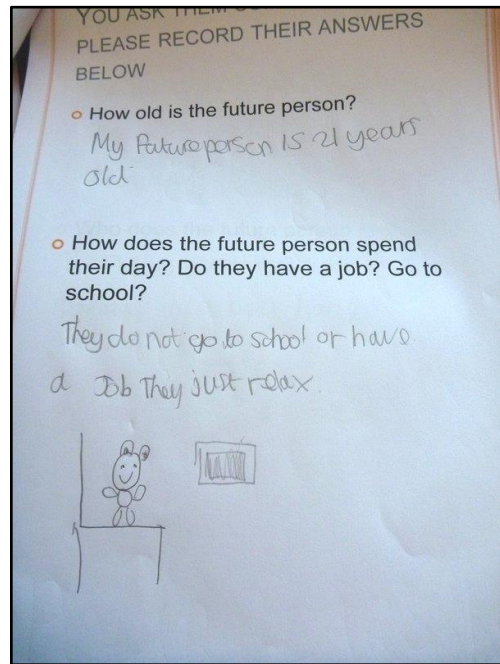


Figure 22: Pause's 'Report from the Future': "My life in the future"

An argument employed to defend young people demonised as Youth as Active is that we cannot blame young people for hanging around on streets when there is little choice of alternative spaces (such as youth clubs) for them to spend time (Topping, 2011). We saw in *Chapter Two*, that there are diminishing numbers of services for young people, and this concerned members of YF quoted at the beginning of this chapter. Conversely, however, CDS texts often point to the opposite problem: disabled youth have less casual 'hanging out' time than their non-disabled peers (Baron, Riddell, et al., 1999; Goodley & Runswick-Cole, 2010; Hughes, et al., 2005; Priestley, 2003). Priestley (2003) highlights that disabled youth's leisure time is often highly structured, concerned not with 'leisure' but filling in time, preparing for a meaningful life without work, giving the family a break and/or managing undesirable behaviour. Furthermore, positioned as eternal children, these kinds of structured activities do not always end at 'adulthood' (Johnson, et al., 2010). Baron et al. (1999) tell us about 43-year-old Clare who is so busy in the week with the 'leisure' activities imposed upon her, that she only has time for her preferred paid employment during weekends:

"Clare is forced to invert conventional social time: during the week she is drawn into a frantic timetable of leisure activities [...]; at the weekends she lives... by working."

(Baron, Riddell, et al., 1999, 494)

What are we denying disabled youth by structuring their lives this way, excluding them from casual ‘hanging out’ time? Pause emphasised to me the importance of having time to “do nothing with her mates”. As a young woman with intellectual impairments in a segregated scheme, Pause is arguably representative of those most often denied this freedom (Hughes, et al., 2005; Murray, 2002; Priestley, 2003). In ‘*The Culture of Working Class Girls*’ McRobbie (2000, originally published in 1977) makes similar points along the axis of gender that I make along axes of disability. She notes that girls had more structure imposed on their lives than their male peers. Furthermore, their perceived vulnerability meant they had less ‘freedom’ to hang around on the streets. There was an expectation on McRobbie’s girls to cook their families’ evening meals which then won them time at the local youth club, before conforming to a 10.30pm curfew. Similarly to the structuring of leisure for Explore members, the school, family and youth club worked to shape McRobbie’s (2000) girls’ lives in particular gendered ways.

To stop at an analysis that used Explore only as an example of the overly-structured lives of young disabled people, however, would be to do a disservice to those involved (staff and young people). As outlined in *Chapter Five*, I realised that Explore offered different things to different young people. For some members, particularly EJ1234 and Gareth, who both aspire to careers as artists, the group’s main benefit was furthering their artistic capabilities; yet this was not the case for all involved. We saw how Sooboo made the most of his time by pursuing his personal interests. Pause seemed to gain greatest pleasure from the social aspects of the group. Pause would often declare, “I’m not going to do anything today; I’m just going to relax”. Appreciative that young people enjoyed the group for different reasons, the staff (some more than others) were not pushy in getting the young people ‘on task’, and would usually respond by asking Pause about her day at college, “been a busy one, has it?” “Yeah”, Pause would reply, sighing, sometimes playfully adding, “...and I’m just a lazy teenager”. McRobbie (2000, 45) writes that “the ‘cultural’ is always a site for struggle and conflict”, and that on first glance her group of working class girls seemed to have less of a culture of opposition and resistance to that usually documented by youth subcultural researchers concerned with male youth (such as Willis, 1977, mentioned above). Neither did I see overt opposition coming from members of Explore. Yet McRobbie (2000) points out that having less freedom from adult surveillance did not mean girls unquestionably accepted what was presumed of them – and neither did it for those at Explore. Rather, the girls’ defiance emerged as

“‘gentle’ undermining [and] subtle redefinition” (McRobbie, 2000, 53). McRobbie notes that whereas boys were more likely to skip school and avoid the youth club, the girls had their own techniques of claiming time for themselves: they attended but did not ‘participate’ in youth club activities; “they were *in* school but not *at* the school” (McRobbie, 2000, 64, original italics). A similar analysis could be made of Pause’s time in Explore. Structural barriers, working along the axis of disability (and perhaps also gender, class and so on), influence how she spent her time. Nevertheless, like Sooboo, Pause had her own strategies of making Explore meaningful, and claiming time from the (semi)formal structures it imposed.

After entering and asserting her desire to ‘do nothing’ Pause would often continue to ‘do nothing’... at least, this is how it was seen by Explore staff who would joke with Pause about her laziness. In 1979 Corrigan (2006) looked at what a group of teenage lads meant when they spoke of ‘doing nothing’ on the street. It is interesting to consider his arguments alongside Pause’s ‘doing nothing’ in Explore. Corrigan argues that for the lads, ‘doing nothing’ was more complex than merely a lack of options. ‘Doing nothing’ was about passing time together through talk and the exchange of stories. ‘Doing nothing’ was a time of ideas. He argues that although a lens of adulthood casts ‘doing nothing’ “as an endless waste of time, an absence of purpose” for young people ‘doing nothing’ is in fact “full of incident” (Corrigan, 2006, 84). Similarly, although Pause was seen as ‘doing nothing’ it was in fact quite the opposite. Like Corrigan’s lads, she would talk and exchange stories; joking with and playfully teasing myself and Explore staff, whilst chatting to other young people. Furthermore, Corrigan poses that the boys did not choose to ‘do nothing’ on the street because the street was the most exciting place they could conceive. However, out of their limited options (the lone pursuits of home or the humdrum of the youth club) it offered most chance of something happening in the future. Similarly, Pause’s choices of how she spent her time were limited. Maybe (although it was never directly expressed), she would have preferred a less formal social setting if given the choice. Nevertheless, she made the most of her time at Explore. By expressing her desire to ‘do nothing’ Pause proclaims her agency to make her own decisions away from the imposed routines of school/college/work, and indeed, Explore. Like McRobbie’s (2000, 64) girls, she was often ‘*in* Explore, but not *at* Explore’. Pause’s negotiations of her time in Explore also included asserting herself as a ‘young person’ (different from adults). Conversely, in order to associate herself with ‘youth’, Pause asserts her passivity (being a lazy teenager, enjoying ‘doing nothing’), yet these

assertions are in themselves actively and playfully demonstrating her agency through their desire to mark herself as a young person, separate to the rat race of adulthood. As Corrigan (2006) teaches us, although frowned upon as laziness and passivity, ‘doing nothing’ can be young people’s lively engagement with one-another and the world around them: one can be an active agent, in what could, on the surface, be considered their most ‘passive’ of activities.

I agree with McRobbie (2000) that culture involves moments of struggle that take place as disabled youth negotiate their time and relationships in Explore. I also follow McRobbie (1990, 45) when she writes that “culture is about the prestructured but still essentially expressive and creative capacities of the group in question”. We have seen the expressive and creative capacities of young people in Explore. These are illustrated not just through their artwork, but also through their negotiations and resistance within prestructured arrangements that are, undoubtedly, imposed upon their lives (Hughes, et al., 2005). Furthermore, we have witnessed disabled youth actively asserting themselves as ‘youth’. The problem is then twofold. I again reiterate that I do not deny young disabled people’s exclusion from spaces and pursuits on par with their non-disabled peers; disablist social oppression which needs to be addressed (and, we see in the next chapter that some young people I spent time with were actively challenging this). However, there are other issues at play which separate disabled young people from discourses of youth: narrow, misleading and ableist conceptions of youth culture influencing perceptions of what it is to be young, meaning disabled youth’s lack of access to youth culture continues to appear reasonable (Titchkosky, 2011). Although we must continue to fight for young disabled people’s access to the same spaces as their non-disabled peers, I argue that we cannot simply demand young people’s access ‘youth culture’. ‘Culture’ is not a ‘thing’ but a series of relationships: “at least in part as the product of collective human praxis” (Willis, 1977, 4). I have shown, disabled youth are already active players within this. If ableist conceptions, as we have seen, have meant chronologically *young* disabled people’s negotiations, struggles and sites of conflict are not recognised within youth cultural discourse, what is it that makes normative conceptions of ‘youth culture’, ‘youthful’? To ask this we are perhaps transported back to the beginning of my thesis: what or who are we talking about when we talk about youth? By considering research question three, what disability and the lived experiences of young disabled people can teach us about youth, we can rethink conceptions of youth culture. It is to this I now turn.

Crippling youth culture: Disabled youth (and their parents) challenging the youth/adult divide

Like youth, and indeed disability, youth culture is full of contradiction. In this chapter we have seen youth culture conceptualised as a place reliant upon the absence of adults.

Therefore it is problematic that disabled youth do not have access to adult-free arenas as without the absence of adults, young disabled people cannot partake in youth culture (Hughes, et al., 2005). I noted in *Chapter One*, however, that others argue youth culture to be more about consumption than chronological age. Generations are brought closer together as youth is not so much a time of life, but a way of feeling (Bennett, 2008; Sweetman, 2001). Ironically, those most financially equipped to buy into this feeling of youth, are the former (and now middle-aged) mods, rockers and punks of original subcultural work (Bennett, 2008; Sweetman, 2001). Arguably, youth culture is not about the pursuits of young people, but a previous generation of ‘youth’, embracing, or perhaps consuming, the “childlike irrationality or lawlessness or carelessness” which Nodelman (1992, 31) argues “is attractively lax, a temptation to be less responsible, less mature, less adult.”

I argue therefore, that reliant upon consumption, youth culture is an arena not recognised by many more young people than just disabled youth. Yet, as those both materially restricted and discursively positioned outside of consumption, disabled youth are particularly ousted from conceptions of ‘youth culture’ (Hughes, et al., 2005). However, although I see the consumerism of Youth for Sale attached to youth culture as problematic, the disavowal of adulthood is appealing. In *Chapter Four* I argued as an inbetween space, youth could be a place of resistance. Research question four asks: what can disability and the lived-experiences of young disabled people teach us about youth? Positioned on the peripheries, disabled youth, crippling youth culture, can help develop more useful conceptions of hybrid spaces in which to become critically young. Hughes et al. (2005, 9) tell us that “[y]ou can’t go clubbing or ‘hang out’ with your Mum and Dad”. I now ask, ‘how come?’ by considering relationships between disabled youth and their parents, before pulling conversations back to youth culture.

I refer back to Pause’s wish to go to a nightclub a place she deemed, “not for old people”, and continue her story. A few weeks after that interview Pause told me that she and her friend were planning to go to a nightclub for under-18s. Although Pause usually got the

bus home, that day her Mum came to pick her up. I recorded the delicate incident that followed:

“Pause’s Mum came in to see her artwork. As they were leaving I shouted bye to Pause, and, remembering about her plans for the week added, “Enjoy your night out”. Pause’s Mum turned to look at her, “we’ve talked about this...” The conversation went on as they left the room. I hope she forgives me!!”

(Research diary, 9th November 2011, Explore fourth session)

The following week I apologised for getting Pause into trouble. I asked her if she had made it to the club and she said she was “still thinking about it”: I was not sure what that meant, but, feeling I had already done my share of damage, did not press her for more information.

Let us consider the differing ways we could conceptualise the above scenario. If we were unaware of Pause’s label of intellectual impairment, we could see it as typical of the kinds of negotiations 16-year-olds experience with their parents; negotiating “being able to go out, to stay out late, to take part in ordinary teenage experiences” (Murray, 2002, 43). Pause and her Mum clash as Pause inhabits the unnerving space of youth; the hybrid of child and adult; the murky period between childhood dependency and adulthood independency (Gordon & Lahelma, 2002). Yet, I have argued continually throughout my thesis, that resting arguments upon the ableist assumption of normative developmental discourse is harmful to disabled youth (Ware, 2005). In *Chapter Seven* participants confirm that the normative expectation on disabled youth is not to strive to adulthood independency, but to remain eternal children (Johnson, et al., 2010). Authors have argued that increased adult surveillance and paternalistic attitudes mean disabled young people are not allowed the same freedoms as their peers to make their own mistakes (Hughes, et al., 2005; Priestley, 2003). The young people at YF agreed with this. Although they acknowledged that most young people battled with their parents, they thought that as disabled young people their situation was harder:

Colin: Just because you’re disabled they don’t let you make your own mistakes. I’ve got a sister who’s non-disabled and she can do what she wants, when she wants and my mum’s okay with that. I try doing the same and I’m not allowed!

Gabby: They might treat us different because we’re in a wheelchair. They might think we’re vulnerable to accidents and things.

Colin: It's the way your parents are brought up. They're brought up with the medical model and they don't really know the social model and because of that they're scared to let go.

(First Futures workshop with YF 23rd November 2011)

To take a social model lens to Pause's story conceptualises it differently. Earlier I drew on Goodley and Runswick-Cole's (2012) '*Reading Rosie*', where the authors offered four different accounts of 11-year-old Rosie. The social model reading they offer includes the following:

“While parents can and do act as allies to their disabled children, they are also the ‘agents of disablism’ (Thomas, 1999) and this is also evidenced by Rosie’s parents’ removing her from mainstream leisure activities and, instead, accessing segregated leisure activities for children with her particular impairment.”

(Goodley & Runswick-Cole, 2012b, 60)

A social model perspective may view Pause's Mum as an 'agent of disablism': overprotectively preventing Pause the freedom she craves, denying her access to 'youthful' spaces, and hindering Pause's strives for adulthood independence. Veck (2002) makes this argument in relation to Ray, a mature student with the label of intellectual impairment who is in the process of leaving a 'special unit' at a further education college which he has attended for a number of years. According to Veck:

“Ray often expressed frustration about his relationship with his mother. ‘The thing’, he [Ray] asserted, ‘is that she doesn’t get it, that I’m a man’. When asked what he meant by this Ray was non-responsive, but he clearly felt that his mother did not consider him to be an adult who was capable of living independently.”

(Veck, 2002, 534)

Veck (2002) goes on to metaphorically conceptualise Ray's life as trapped in a 'parent-child' discourse, sustained as “staff [at college], officials and Ray's mother act as a 'net-like organisation' that fixed 'a normative gaze' upon Ray” (532). I do not know Ray or his relationship with his mother, and do not wish to discredit this particular story. Yet, after spending time with young disabled people it was important for me to take heed from Ryan and Runswick-Cole (2008). They note that “the actions of mothers have been interpreted as constraints within their [disabled] children's lives, limiting their opportunities and aspirations” (Ryan & Runswick-Cole, 2008, 200), and urge us to consider that “[p]arents may not be pathologizing their children but trying to operate within a disabling set of practices” (201). My problem with Veck's (2002) interpretation

of Ray's story is not so much the positioning of Ray's mother (of which, I am not in a place to judge), but that Veck uses the mother-disabled child relationship in a way which demonises *all* mothers of *all* disabled children. Not only is Ray's mother blamed for him not being allowed to live independently (in which she may or may not be a player), but the relationship of parent, or more specifically, mother, and disabled offspring, is used as a metaphor to negatively conceptualise the normative gaze surrounding Ray.

Arguably, the demonization of mothers of disabled children (Ryan & Runswick-Cole, 2008) is another unhelpful consequence of the neoliberal pedestalling of (adulthood) independence, which disabled people, for good reason (we see in *Chapter Seven*) have felt the need to assert themselves within (Ferguson & Ferguson, 2001). To assert themselves as adults, disabled people have disputed that they are dependent upon a non-disabled population (Hughes, 2001). As the discourse of youth as becoming-adult relies of an assumption of becoming independent from one's parents (Gordon & Lahelma, 2002), the relationship between (dependent) child and (depended upon) mother been questioned:

“The (often) non-disabled status of the mothers [...] propels them into the difficult and contentious debates about the role of non-disabled people within the lives of disabled people”

(Ryan & Runswick-Cole, 2008, 199)

In *Chapter Seven* I argue that binary divisions between dependence and independence create problems for disabled people using paid assistance (Gibson, 2006). We see the similarly problematic nature of strict boundaries drawn between carer and cared for in mother/child or other unpaid or informal caring relationships (Morris, 1991; Walmsley, 1993). Furthermore, dependence/independence dualities do not only result in the demonization of non-disabled mothers for restricting the independence of their disabled children (Ryan & Runswick-Cole, 2008), but the competence of disabled mothers is also brought into question (Walmsley, 1993). The assumption is that a (dependent) disabled mother cannot care for, or be depended upon by, a non-disabled child (Morris, 1991, 1997). I explore the implications of this for young disabled women in *Chapter Eight*. In this chapter, however, it is important to note that these binaries do not reflect the lived-realities of young disabled people's lives. Murray (2002, 43) reports that when asked about their relationships with their parents, young disabled people “agree[d] that their parents sometimes worried about them too much, [but] understood why this was the case. They thought it was reasonable for their parents to worry (all of them had had very

unpleasant experiences), but were keen to work out ways of being able to go out, to stay out late, to take part in ordinary teenage experiences”. This was a thought echoed by those at YF: their parents’ protectiveness was at times frustrating. However, this was not their parents’ fault, but due to parents not knowing alternative discourses of disability. It was a matter of teaching them different ways of thinking about disability. The importance of hybrid spaces for child/parent, disabled/non-disabled, youth/adult discussions, therefore, becomes clear (an argument I return to in the concluding chapter).

Most participants looked forward to a time when they would be able to have more control over their social lives. Sometimes, particularly at YF, disabled youth wished their parents allowed them the same freedoms as their non-disabled siblings. Many envisioned their lives becoming more separate from their parents as they grew older. Yet, there was not a desire to escape ‘parental constraint’. In Explore, feelings were in fact to the contrary. Pause, for example, could not decide on the ideal living situation for her future world. She flitted between living with her family or with her friends. In an interview she told me she may want to move from her Mum’s house when she was “about 30”. Eventually she decided the best situation was to have two big houses next door to each other, one for her family and another for her friends. She could switch between the two. This is reflected in a picture entitled “*My Life in the Future*”, where we see a ‘Rainbow Castle’ for Pause’s family to live in, next door to a more (to put it in Pause’s words) “ordinary castle” for her friends.



Figure 23 Pause's "ordinary castle" for her friends, and "rainbow castle" for her family.

Pause does not want to be constricted to *only* spend time with her family. Yet neither does she see her parents as constricting her future adulthood endeavours, or a hindrance to time she may choose to spend with her friends. Goodley and Runswick-Cole's (2012c) findings are similar. In relation to a project considering disabled people's resilience through the life course, they write:

"A key element in the promotion of resilience [for disabled youth] appears to relate to the support of the extended family [...]. This also suggests that while families offer support and alliance these same families share experiences of disablism. Inevitably, as young people grow older then the locus of support expands to include friends."

(Goodley & Runswick-Cole, 2012c)

Research question three asks what disability and the lived-experiences of young disabled people can teach us about youth. After listening and considering the lives of young disabled people I argue that youth is not about becoming-independent. Rather, it is about dynamic and increasing numbers of interdependencies. To appreciate dynamic interdependent relationships, is to appreciate that dependencies are not one directional (Walmsley, 1993). After conducting research around caring roles of women with intellectual impairment, Walmsley writes:

“Examples of the views and experiences of women with learning difficulties show that caring and dependency, far from being dichotomous, are on a continuum. We are all dependent to a greater or lesser degree on others. And so-called dependents can themselves be carers.”

(Walmsley, 1993, 136)

We are urged to appreciate that “who is the carer is in the eye of the beholder” (Walmsley, 1993, 136). “Expand[ing] our definition of caring to encompass not just physical tasks but also the emotional” (Morris, 1991, 167). Considering the interdependent, multidirectional nature of caring relationships, can help us to a) question why young people breaking away from their parents has come to be seen as such a ‘natural’ Western phenomenon; and b) rethink child/parent relationships in ways which are more inclusive to the lived-experiences of young disabled people.

In light of the above let us consider Pause’s dealings with her mother again. Thinking back to McRobbie’s (1990, 45) definition of culture, we remember that culture is about the “prestructured but still essentially expressive and creative capacities of the group in question”. Firstly, we should not deny the unique (prestructured) experiences of Pause’s family, which are no doubt influenced by dis/ableist structures and attitudes (Ryan & Runswick-Cole, 2008). Colin and Gabby from the YF earlier told us that their parents were more protective of them than their non-disabled siblings. Taking heed of this and other studies (Baron, Riddell, et al., 1999; Horgan, 2003; Murray, 2002; Priestley, 2003), we can speculate that Pause’s Mum *is* likely to be more protective of Pause, due to her label of intellectual impairment. However, we should also listen to Murray’s (2002) participants who told us that although their parents (like all parents) could sometimes be frustrating, they felt their parents’ worries were justified. Considering research question one, what dangers young disabled people face if normative discourse remains unquestioned, over the course of my thesis we see growing-up disabled in dis/ablist world can be both difficult and dangerous (Goodley & Runswick-Cole, 2011c). We also know “the ‘cultural’ is always a site for struggle and conflict” (McRobbie, 2000, 45). Despite connotations of passivity, disabled young people such as Sooboo and Pause are not simply passive in accepting the dis/ablist structures which surround them, rather they “exercise agency and resist” (Reeve, 2002, 493). We see Pause’s negotiations with her mother above. Taking McRobbie’s conception of the cultural into account, it seems youth culture is not so much about adult-free space, but about negotiations, moments of struggle, conflict and resistance, between any numbers of actors, embodying numerous intersectional identities: age being just one.

Discussion

I began this chapter concurring with CDS scholars that young disabled people are denied access to the same spaces as their non-disabled peers (Priestley, 2003). I maintain the importance of fighting for young disabled people's right to be/come alongside non-disabled youth. Yet fighting for disabled young people's right to access space is different to arguing for young disabled people to have access to 'youth culture'. Normative conceptions of youth culture rest upon consumerist and normative developmental discourse. 'Youth culture' is abstracted from young people (Bennett, 2008; Hughes, et al., 2005; Sweetman, 2001); especially disabled youth (Hughes et al., 2005). Asserting young disabled people are denied access to youth culture means youth culture remains a thing "it sometimes seems as though some people have [...] and some don't" (Titchkosky, 2011, 3). This renders disabled youth passive and outside of youth culture, and fails to expand our notions of youth culture to include disabled youth's current cultural negotiations, instead working to sustain unhelpful binaries.

In *Chapter Four* I offered a theoretical romp through theories I thought useful in helping me think-through the 'inbetweenness' of youth and disability. At the end of this chapter I argue that considering how disabled youth 'do youth' helps us consider 'youth culture' more inclusively. In fact, I propose that rather than youth culture, we should muse around what critically young cultural spaces may look like; spaces which do not stipulate chronological age, nor abstracted consumerist and dangerous discourses of 'youthfulness' (see *Chapter Three*). Rather, hybrid spaces in which we can all be critically young. Essential to this space is the breaking down of binaries, as and when it is safe to do so. I develop this concept over the remainder of this thesis. I outline here, however, what this chapter has taught us about being critically young.

The first binary critical youth asks us to address is disabled/non-disabled. As Titchkosky (2011, 4) reminds us "questions of access can arise for anyone, at any time, and anywhere for innumerable reasons". I earlier used the 'reasonable adjustments' requirement of the *Equality Act 2010* to concur with Titchkosky that "whether or not the reasons for lack of access are judged good or bad, the social activity of people seeking reasons fosters the sensibility that lack of access is reasonable" (Titchkosky, 2011, 77). Thus, people who are not granted access are deemed unreasonable bodies. Seeking reasons for disabled people's access confirms, rather than challenges our sense of

normalcy (Titchkosky, 2011). This is not to say we have reached a time where disabled youth's identity political battles can stop. In *Chapter Seven* I consider my young disabled participants' fights to be accepted as becoming-adults. However, research question three and four ask me to consider what disability and the lived-experiences of young disabled people teach us about youth, and what youth and the lived-experiences of young disabled people teach us about disability. Drawing on Titchkosky (2011), I argue that as disability and youth researchers we need to use questions of access to ask how disabled youth continue to be considered reasonably excludable types. In this chapter I have therefore used disabled youth's exclusion from spaces their non-disabled peers have access to, to address wider questions around the positionality of youth and disability, as they relate to conceptions of 'youth culture'.

Feminist youth subcultural work has helped me question disabled/non-disabled binaries in relation to youth culture. Feminist youth subcultural researchers criticised dominating youth subcultural work for focusing on male youth (McRobbie, 1980, 1982, 1990, 2000; McRobbie & Garber, 2000). They argued the lives of girls were not deemed excitingly deviant enough to be considered by youth subcultural researchers (McRobbie & Garber, 2000). I have argued that positioning disabled youth as passive may have contributed to youth subcultural researchers' failures to incorporate experiences of disabled youth. Research question two asks: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient? I utilised feminist youth subcultural arguments to show disabled youth actively negotiating their own time and space within the pre-structured elements of their lives. Thus, we see that young disabled people are far from Youth as Passive. Rather, they are active agents negotiating dis/abled worlds. In response to research question two I therefore maintain the importance of transdisciplinary engagement between CDS and other disciplines, such as youth subcultural studies.

Engagement with youth subcultural research prompted me to consider what we mean when we speak of 'culture'. I work from definitions which presume culture to be a) "at least in part as the product of collective human praxis" (Willis, 1977, 4); b) "about the prestructured but still essentially expressive and creative capacities of the group in question" (McRobbie, 1990, 45); and c) involving moments of conflict and struggle (McRobbie, 2000). If we take the logical step and reason that when the above are instigated by 'youth' we are witnessing 'youth culture', we see that young disabled

people I was spending time with *were* part of youth culture. Many of the moments of conflict and struggle arose not so much despite of but because of dis/ablist physical and attitudinal barriers young people faced. When we take notice, young disabled people teach us the falsity of equating disability with passivity. However, they also help us to rethink ‘youth’ as it relates to ‘youth culture’. The spaces young disabled people inhabited were not adult-free. Moments of conflict were therefore not restricted to those conceived as youth, but took place cross-generationally.

A critical youth cultural space therefore also needs to be vigilant to youth/adult divides; there are multiple reasons for this. Firstly, considering youth culture happening only within adult-free arenas may exclude disabled youth requiring assistance. As I expand upon in *Chapter Seven*, young disabled people I spoke to concurred with those in Murray’s (2002) study, that support was not a hindrance, but an avenue to adventures. Why should these adventures, if aided by adults, be considered outside a discourse of youth culture? Secondly, presuming youth culture depends on a lack-of-adults relies upon and concretises dominant conceptions of developmental discourse, of what it is to be ‘adult’. I argued in *Chapter One* that normative developmental discourse excludes disabled youth. It presumes young people will grow out of youth, to become normative adults. Those that do not are positioned as lacking. Furthermore, a youth/adult divide, leads to the final unhelpful binary I feel it productive to unpick: parent/child.

I have considered parent/child relationships in this chapter, and do so further in *Chapter Eight*. I offered a number of readings of a scenario where Pause wished to visit a nightclub with her friend; something her mother was concerned about. Synthesising youth subcultural and CDS texts, I highlighted that we could view Pause’s negotiations in a number of ways. Firstly, we could view Pause’s situation as no different from those of non-disabled teenagers. I worried, however, that this denied the dis/ablist structures that impact upon Pause and her family (Ryan & Runswick-Cole, 2008). Prompted by Goodley and Runswick-Cole (2012b), therefore, I offered an alternative social model reading. Yet, there were problems with this reading too. It was easy to blame Pause’s mother for restricting her opportunities to reach adulthood independence (Veck, 2002). Thus, failing to appreciate that Pause’s Mum “may not be pathologizing [Pause] but trying to operate within a disabling set of practices” (Ryan & Runswick-Cole, 2008, 201). Furthermore, drawing on what I was told by participants, I argued that this parent/child divide did not represent the lived-realities of young disabled people’s lives. I

proposed we should begin to think about the interdependencies of relationships as they relate to disabled youth; arguments that I expand over the next two chapters of analysis. In response to research question three: what can disability and the lived-experiences of young disabled people teach us about youth? Disabled young people, such as Pause, taught me that youth is not about becoming-independent, but a time of dynamic and expanding networks of interdependency.

What does this mean for our conceptions of youth culture? At the end of this chapter I conclude that dominant ideas around youth culture are unhelpful. I believe it more productive to consider how we can develop cultural spaces in which to be critically young. These critically young spaces would not require chronological youth, or buying into the consumer culture we have come to associate with youth (Hughes, et al., 2005). They may, however, mean engendering the “temptation to be less responsible, less mature, less adult” (Nodelman, 1992, 31) in order to be critical of and resistant to adulthood normativity. We need to take the position of disabled youth as an opportunity to develop hybrid spaces of cross-generational negotiation, resistance, interdependence. I turn over the next two chapters to consider how disabled youth can help us to do this by reconsidering notions of Youth as Active and Youth for Sale alongside the stories of disabled youth.

Chapter Seven

Disabled Youth Becoming-Independent-Adult: Crippling Youth as Active

Introduction

As a disability researcher, critiquing potential dangers of pedestalling independence, I was surprised to find that I had written in my research diary, in relation to my Icelandic friends, Embla and Freyja, “it’s good to hang out with such strong, independent women”. Taken aback, I questioned what I meant. I certainly did not mean ‘independent’ to be used in its neoliberal, ‘every-man-for-himself’ (sexist) ‘stand-on-your-own-two-feet’ (ableist) fashion. Neither did I mean strength to come with masculine and ableist connotations. Yet strength and independence do come to mind when I think of Freyja and Embla. I have written elsewhere about how in another project with young disabled people I questioned my own notions of independence (Slater, 2012a). Spending time with Embla and Freyja challenged this further. In this chapter I address research question three, what can disability and the lived experiences of young disabled people teach us about youth? I do this by taking the becoming-adult status of Youth as Active and thinking it through alongside what I argue to be my young disabled participant’s crip conceptions of independence.

Chapter One explained that Youth of Active begins from the assumption that young people are active becoming-adults: striving for a) an adult identity and b) independence (Priestley, 2003). *Chapter Six* played around with this term ‘activity’, highlighting young disabled people’s active resistance to time frames and structures imposed upon them. I also posed the possibility of breaking down youth/adult, in/dependent binaries to develop spaces of critical youth. I start this chapter by sharing the stories of young people actively fighting to be accepted as becoming-adults. These battles take the form of identity political fights, which trouble dominant discourses of disability. Thus, the stories of young disabled people address research question four: what can youth and the lived-experiences of young disabled people teach us about disability? I highlight that the solidarity of disability politics helps disabled youth resist internalising the oppression of psycho-emotional disablism (Reeve, 2002). Furthermore, arguing for their place within

normative adulthood lessens dangers of disposability (Giroux, 2009). Research question one, however, asks, what dangers young disabled people face if normative discourse remains unquestioned. I worry that asserting themselves as becoming-adults denies young disabled people the time and space to ‘be young people’ and the opportunity to become in any number of possible ways. I therefore take my participants’ calls to be accepted as becoming-independent-adults as an opportunity to reconsider adulthood independence. Reflexively considering ethnography in the ILC in Iceland, I argue that disabled youth are crippling meanings we attach to ‘independence’; and therefore Youth as Active and what it means to become-adult. I begin my exploration of youth, disability and becoming-adult, through my time with Youth Forum (YF).

Youth, disability and becoming-adult

I introduced the first futures workshop at YF by asking young people to think of things which annoyed them (see *Figure 6, Chapter Five*). Young people complained about the structural barriers they faced. Annoyances included “inaccessible buses”, “taxis with high steps”, “inaccessible buildings” and “badly made equipment”. Discussion for the majority of the session, however, revolved around how young disabled people were treated by others (mainly, non-disabled adults). Attitudinal annoyances included “people telling you what to do”, “patronising attitudes” and “people not treating you like an adult”. I asked the group how they thought these attitudes could be changed. The subsequent conversation went as followed:

Jenny: So how could we change people’s attitudes ready for our best-ever future world?

Colin: Probably like doing outreach. Talking to people to help them understand.

Sarah: Getting your views across about what it really is to be a young disabled person so that they don’t patronise you – education isn’t it.

Jenny: And what would you tell them?

Colin: That we’re no different from any other person and that we like to be treated equally.

Sarah: and want the same things.

(Transcript from first futures workshop with YF 23rd November 2011)

Morris (2002, 11) writes that “[y]oung disabled people have the same aspirations as their non-disabled peers but require specific action to tackle the disabling barriers they experience”. Participants from YF agreed with Morris: there were strong views that people should know disabled people are “no different from any other person”. They told

me that they faced both physical and attitudinal barriers which meant they were treated differently to their non-disabled peers. Those around them failed to consider them as active becoming-adults.

Stories of paternalism were shared between young people and youth workers. Fay, an actress in her 20s, talked about her drama group, where she is the only disabled person: “people think I’m like 13 and they just look down at me like a kid and they won’t let me do this and that”. The group discussed a colleague with ‘restricted growth’ at the organisation who gets “treated like he’s a seven-year-old child, nobody will believe him that he’s a married guy with two kids and that he’s a professional guy, an MBE!” A youth worker shared the following:

“I hate being treated like a 10 year old when I’m a 51 year old professional youth worker. This morning I had to be in dead early so I’m getting on the train at 6 o’clock and it’s still pitch dark and I’m like that (sleepy face): ‘where’s the train?’ And some guy comes up behind me and goes “let’s go, weeeeeeee! Whoopee! We’ll soon have you away - honk!” I’m thinking – would you talk to another 51-year-old guy that’s getting on a train like this?”

To which two young people replied:

Fay: “That’s patronising!”

Gabby: “It’s stereotyping, without actually knowing you.”

(Transcript from first futures workshop with YF 23rd November 2011)

As argued in *Chapter One*, unquestioned ableist adulthood rhetoric positions disabled people as eternal children (Johnson, et al., 2010). My approach is to question these ableist signifiers. *Chapter Two* outlined, however, that other CDS scholars have taken a different approach: highlighting the barriers faced by disabled youth in their transitions to adulthood (Hendey & Pascall, 2002; Morris, 1999, 2002). The latter was also the tactic taken by those at YF. Young people at YF thought disabled young people should be considered becoming-adults, just like their non-disabled peers. Young people wanted the freedom to try things out and carve their way to adulthood independency. A poster (*Figure 24*) made by Claire, a young woman with the label of intellectual impairment, illustrates her desire to be considered within the norm:



Figure 24: "Treat me normally" poster

Claire's poster shows an alien alongside the thought "treat me normally" and a request for "freedom". It resulted from an earlier discussion where she told me her teacher at college makes her "feel like an alien". Research question one asks what dangers young disabled people face if normative discourse remains unquestioned. Claire's poster expresses the felt reality of Otherness and alienation when disabled youth are positioned outside normative discourse. This alienation is a form of psycho-emotional disablism (Goodley & Runswick-Cole, 2011c): "a form of disablism [that] undermines the emotional well-being of disabled people and can be just as disabling as structural barriers" (Reeve, 2002, 493). Reeve (2002) warns us that psycho-emotional disablism can lead to disabled people internalising feelings of Otherness and inadequacy and beginning to believe the engrained falsities that surround them. Having access to peer support and disabled role models, however, can help disabled people resist internalising oppression (Reeve, 2002). YF gave disabled youth access to disabled peers and older role models to talk-through shared feelings of oppression with (Murray, 2002). After Claire told the group her teacher "made her feel like an alien", the young people shared stories of teachers "not giving me any respect", being "bossy" and "in your face". One of the youth workers then asked the group if they thought they were treated differently as young disabled people:

Margery (youth worker): Do you think she was stereotyping you, Claire, because you're learning disabled?

Claire: Yeah, she was dead patronising.

Margery: What sort of staff would you like to support you at college? What would you like them to be like?

Claire: To be nicer and have more patience. She did *not* look patient when she kept going in my face like that.

(Transcript from first futures workshop with YF 23rd November 2011)

Garland-Thomson (2002, 27) uses the term 'academic activism': "the activism of integrating education, in the very broadest sense of that term. The academy is no ivory tower but rather it is the grassroots of the educational enterprise". Above we see young people and youth workers engaged in academic activism; together critically theorising the situations they faced as disabled people. They do this largely through identity political arguments. The importance of space for such discussion should not be underestimated. As well as beneficial to individuals involved, those at YF join other disability activists and scholars to challenge assumptions of disability as a devalued difference through an argument of 'sameness'. As Colin put it above disabled young people are "no different from any other person". As we go through this chapter I will look further at the paternalism in the lives of young disabled people. I considered this to a degree in *Chapter Six*: particularly exploring relationships between disabled youth and their parents. Young disabled people asserted their parents needed alternative ways of think about disability, outside of medical discourse. I argue that learning from disability to think differently about youth and adulthood can also help challenge the positioning of disabled people as forever young. Furthermore, it can relieve the pressure on disabled youth to (as outlined in *Chapter Four*), mimic normative adulthood. It is to this I now turn.

Disabled youth and dangers of adulthood mimicry

Arguments of 'sameness' were also employed by disabled youth in Iceland. The following story was told by Freyja to introduce the philosophies of independent living (IL) at a conference:

"You go into a shop and in front of you are two pairs of shoes: some beautiful high-heeled shoes, and some ugly, boring, 'practical' ones. You tell the shop assistant you want the high-heels. You'd be surprised if she turned to you and said, "are you sure that's a good idea, I don't

think they'll be good for your feet, what if you fall? You have to buy the comfortable flat shoes". You'd tell her that it's up to you which shoes you buy, and you want the high-heels. But these 'it's for your own good attitudes' are the kind disabled people face on a daily basis. IL is about having the freedom to make your own decisions, and make your own mistakes, like everybody else."

(My telling of a story told by Freyja in Haraldsdóttir & Ágústsdóttir, 2012)

Freyja argues for disabled women's right to buy high-heeled shoes "like everybody else". As Crow (2012, 138) writes, it is "the basic principle of equality that underpins the disabled people's movement". We have seen throughout my thesis some of the contradictory rhetoric which surrounds disability; disabled people at once "perceived as being helpless, child-like and dependent" but also "seen as something to be feared and avoided" (Reeve, 2002, 501). Reeve (2002) warns us that living within this contradictory identity is harmful to the emotional wellbeing of disabled people. Positioning themselves as "like everybody else" can help resist feelings of inadequacy. Yet from my thesis we also see that youth is a similarly contradictory space to inhabit. Following Reeve's (2002) logic, therefore, living with the contradictory identity of youth could be similarly harmful.

When young disabled people and their allies, however, argue young disabled people are the same as other young people, they are not usually arguing for a place within a discourse of Youth as Passive. Nor do they assert that disabled youth are disruptive Youth as Active (see *Chapter One*). Rather, they place disabled youth as active becoming-adults (Morris, 2002), or in the case of Freyja's story, becoming-women (considered further in *Chapter Eight*). Davis (2002) however warns us that fighting for equality can mean fighting for the rights of the normative subject, rather than a society celebrating difference. We see this in Freyja's story. The argument assumes we share common-sense knowledge that women have a right to buy high-heeled shoes. Buying high-heeled shoes is what women 'should do', and they symbolise what women 'should be'. It resonates with *Chapter Three's* discussions of Youth for Sale.

However, for me to be sceptical of the normative disability rights approach employed here fails to appreciate the political context of the story. This story was not told within an academic setting but a conference introducing a new law that that would give disabled people the right to hire their own PAs. The hall was overflowing with politicians of varying levels (including the Icelandic president and the elected mayor), disabled people

of varying ages, some of whom were affiliated to and/or representing disabled people's organisations, parents of disabled children, and those employed as PAs and/or other disability 'professionals', along with their union representatives. There was conflict within the room as to whether the new law was 'feasible'. Arguments against feasibility were:

1. It was expensive.
2. Disabled people would take advantage by taking on more assistance than required.
3. Current services did not have time to implement changes.

Like in current British politics, disabled people were seen as "a fiscal burden but one who deserves the support and succour of the community" (Hughes, 2001, 24) (see *Chapter Two*). The room was full of Mr Reasonables harbouring ableist perspectives that "in a democracy disabled people should be treated fairly on the basis of toleration. Such a stance does not however suggest that disability is considered a reasonable and an acceptable form of diversity, or indeed that disability can be celebrated" (Campbell, 2012, 213).

There was acknowledgement that disabled people needed assistance and a place to live. Yet many felt this should be a charitable offering disabled people should be grateful for, rather than in control of (Barton, 1993). To challenge this, Freyja talked within 'reasonable' rhetoric of fairness and equality. She was representing the ILC. To make disabled people's right to assistance 'common-sense' she set it within a normative neoliberal consumerist discourse. She used the argument that disabled people are "no different from anybody else" to plainly spell out the lack of autonomy forced upon disabled people as an injustice (Priestley, 2003). Furthermore, by strategically 'buying into' stereotyped feminine roles, Freyja was asserting herself as female, a gender identity disabled people are often denied (Garland-Thomson, 2002) (see *Chapter Eight*).

Colin from YF also felt he needed to assert himself within normative discourse. A youth worker described Colin as having 'his fingers in a lot of pies'. After leaving college Colin became very involved in disability politics: fighting his own battles in relation to PAs and accessible housing, mentoring other young disabled people, and taking part in wider activism, on top of volunteering as a web designer for a local business. When I wished Colin a good weekend, he complained about how quiet weekends were, and that he could not wait for Monday. Murray (2002) notes that disabled young people's leisure

time is likely to be spent engaged in solitary activities, such as alone on the computer. Colin's weekend pursuits reflected this. As explained in *Chapter Six*, Colin is reliant on taxis for travel so was more mobile during the week because the DPO and his workplace subsidised his transport. Weekends were lonely and boring. An interview between Colin and I went as follows:

Colin: I went to a conference and they said statistics have shown disabled people work more and aren't off sick as much as non-disabled people.

Jenny: Do you think that's feeling you need to prove yourself? That you can't have a day off because they'll take any excuse to dismiss you?

Colin: Yeah, no matter how ill I am I still struggle on.

Jenny: I can imagine! Are you worried people will be like, it's 'cos he's a disabled person ...

Colin: Yeah. It hacks me off that people go out during the week, get absolutely hammered and then phone in sick the next day when there're people, disabled people out there, wanting to work and we can't get jobs. Recently, Philip Davis, the MP, said disabled people are scroungers ... and that all the disability allowances get spent on trying to get things that non-disabled people have to work for - I don't agree.

(Interview with Colin 1st December 2011)

Colin's positive outlook means that he sees other people's low expectations as an opportunity to prove them wrong. Entering college, for example, he was told the course he later passed would be too stressful for him to cope with. However, he also articulated that feeling the need to prove himself above and beyond his non-disabled peers was something he was "sick of doing". In *Chapter Six* I took a critical look at youth culture. I argued normative conceptions of youth culture are a far cry from the lived-realities of disabled young people's lives. Colin's words above support this. As a disabled person, embracing "a temptation to be less responsible, less mature, less adult" (Nodelman, 1992, 31) is not an option for Colin, as he feels it would have immediate consequences. Although it seemed Colin was challenging rather than internalising the psycho-emotional disablism of being portrayed as a scrounger (Reeve, 2002), the feelings were hurtful nonetheless. Furthermore, Colin had an extra need to prove himself adult-enough to work, as to not do so meant being restricted to his parental home. Colin's story shows that disabled young people may feel pressured to meet signifiers of adulthood more than their non-disabled peers in order to prove themselves 'capable adults' and escape paternalising and infantilising discourses of passivity (Murray, 2002; Priestley, 2003). This is more the case than ever under the scapegoating welfare-cutting gaze (Garthwaite,

2011). For young disabled people and their advocates to assert themselves in discourses of adulthood is not so much a ‘choice’ or a ‘desire’ but a means of survival.

A story Freyja told me about a conversation she had with the mother of a young man with ‘intellectual impairment’ supports my above argument:

Mother: Bjarne was annoyed last night.

Freyja: Oh dear, what about?

Mother: I’m not sure. I kept asking him but never got to the bottom of it.

Freyja: Sometimes we don’t really know ourselves.

Mother: Yeah but with Bjarne I constantly want a reason! Without a reason it’s easy for other people to call it ‘challenging behaviour’. I want to be able to say, “He’s pissed off because you didn’t let him choose his own dinner, you would be too!”... But he must get annoyed with my constant asking. I never do it with my other kids; they’re allowed to just be moody teenagers.

(My version of Freyja’s conversation, based on notes from research diary 25th February 2012)

By advocating for Bjarne, feeling she had to justify his actions as adulthood ‘rationality’ not ‘challenging behaviour’, his mother sensed she may be denying him the opportunity to be a teenager in a bad mood. Arguments made in *Chapter One*, that we should be wary of the becoming-adult status of youth, again become relevant. I noted in *Chapter Four* that CDS scholars have critiqued services for disabled youth as attempting to carve them into normative adults (Goodley & Runswick-Cole, 2010; Murray, 2002; Priestley, 2003). We saw the realities of this in *Chapter Six*, when I was told not to encourage Sooboo to talk about teeth. Combined with feeling the need to ‘prove people wrong’ can mean there is little space for the multiplicity of possible ways of becoming disability offers us (Shildrick, 2009). Furthermore, neither does it allow disabled young people the time and space to enjoy ‘being young’ (in whatever form this may take). Ferguson and Ferguson (2001, 71) have similar worries. They write, in respect to their disabled son, who “over the years has collected a variety of labels” being accepted into the ‘world of adulthood’:

“Do we emphasize his differences and try to avoid the conclusions of inferiority that society has traditionally attached, or do we emphasize his sameness and risk perpetuating the same social rules and expectations that have already unfairly excluded him? Should Ian’s adulthood look the same or different from the dominant cultural models, or from any alternative models presented by other parts of the disability community?”

(Ferguson & Ferguson, 2001, 87)

The Fergusons worry that establishing their son's 'adult' status denies him the cultural experience of becoming as a disabled person, but perhaps out of kilter with normative adulthood. They argue that ILMs fighting for disabled people's inclusion within, rather than questioning Western individualism excludes those with the most 'severe' impairments. If barriers to sameness are removed, and some disabled people continue to fail, blame can be placed upon individuals meaning their "exclusion from culture is more justified than ever" (Ferguson & Ferguson, 2001, 84). As Ware (2005) argues, whilst there continues to be a Western drive for independence, disabled people will never be fully accepted, as they remind non-disabled people as their potential for dependence.

I was aware of these conflicting arguments throughout fieldwork. By critiquing signifiers of normative adulthood, celebrating disability for 'not-fitting-in', was I doing a disservice to disabled youth wanting to be considered within normative discourse? As I outlined in *Chapters One* and *Four*, although I believed adulthood a farce, I could pass as adult; an option not on offer to some of my disabled peers (Ferguson and Ferguson, 2001). I felt in a position where it was safe to reject my status of adult, but for my participants mimicking adulthood was a political urgency, to avoid internalising psycho-emotional disablism (Reeve, 2002), and resist disposability (Giroux, 2009). As is the case in ethnography analysis was a continuous process (Tedlock, 2000). I was therefore worrying about the above as I left for Iceland (see *Chapter Five*). Spending time with young disabled people at the ILC helped me think-through my concerns. I found that in their mimicry of adulthood, they were in fact mocking adulthood. Expanding our definitions of what it is to be youth as becoming-adult. I consider this in *Chapter Eight* in relation to gender and sexuality. For the remainder of this chapter, however, I draw upon my time in Iceland to further explore the adulthood signifier of independence.

Mocking adulthood, crippling independence

'Good' Youth as Active is about youth as becoming-independent-adult (Wyn & White, 1997). In this chapter we have witnessed disabled youth feeling excluded from this normative discourse, and that they need to assert themselves within it. Although I appreciated the political urgency of positioning disabled youth as becoming-independent-adult, I also worried it restricted young disabled people's other ways of being/becoming. Wanting to be an ally to my young disabled peers, I was in a quandary. Like the Fergusons (2001, 87), I wondered whether I should "emphasize [young disabled

people's] differences and try to avoid the conclusions of inferiority that society has traditionally attached, or [...] emphasize [young disabled people's] sameness and risk perpetuating the same social rules and expectations that have already unfairly excluded [them]." To explain how I worked through these dilemmas, I turn to my time with ILM in Iceland to further explore 'independence'.

Freyja and Embla, directress and chairwoman of Reykjavik's ILC, live what they (and I – we saw in the introduction to this chapter) consider to be independent lives. Many of their daily battles involve asserting themselves as independent.

"Fundamental to the independent living philosophy is the idea that all individuals should have the opportunity to make choices in performing everyday activities, including managing one's personal life, participating in community life and fulfilling social roles, such as marriage, parenthood, employment and citizenship"

(Gibson et al, 2009, 318)

When Gibson et al. (2009, 322) asked a user of personal assistance what IL meant to him, he "captured three facets of independent living as living apart from parents, living outside an institution and having control over one's day-to-day activities". The philosophies of IL sit with literature arguing for disabled young people's right to be considered youth as becoming-adult (Hendey & Pascall, 2002; Morris, 1999, 2002), or Youth as Active. Yet it seemed for young people in Iceland, independence meant more than this. Freyja, Embla and others at the ILC recently published a book entitled '*Free*'. Here Freyja tells us that to her IL "means being able to make my own decisions, create my own lifestyle so I can be fully myself" (Freyja cited in Haraldsdóttir & Sigurðardttir, 2011, 28); whereas for Embla IL "means being able to be a woman" (Embla cited in Haraldsdóttir & Sigurðardttir, 2011, 7). Others tell us more about the meaning of IL:

Ragnar (four-years-old): "To me independent living means being able to live at home with my mom, dad and siblings as well as going to a playschool like most 4 year old boys do." (8)

Áslaug (tenth grade at school): "To me independent living means being able to control how to shape my own life" (11)

Gísli (26-year-old man): "To me independent living is being able to study at the University of Iceland and to work as an organist in Sunday school at my church" (12)

Ásdís (sign language professional and poet): “To me independent living means being able to have my own family and a dog” (15)

Karl (25-year-old artist and security guard): “To me independent living means being able to live on my own and do what I want, when I want” (16)

Hallgrímur (33-year-old computer specialist): “To me independent living is the key to being able to live a free life on my own terms” (19)

Bjarney (10-years-old): “To me independent living means being able to play in my leisure time the way I want to” (20)

Jón (38-year-old swimming coach): “To me independent living means having the opportunity to live life to the fullest” (23)

Snædís (second grade college student): “To me independent living is a dream that must come true” (24)

Finnbogi (10-years-old): “To me independent living means being able to choose to play Shrek on costume day at my school” (27)

(Haraldsdóttir & Sigurðardttir, 2011)

Although conceptions of IL such as “being able to live on my own and do what I want, when I want” (Karl in Haraldsdóttir & Sigurðardttir, 2011, 16) err towards conventional conceptions of independence, for others it had different meanings: being able to play Shrek on costume day or to live life as a woman (I consider Embla’s assertion that IL enables her to be a woman further in *Chapter Eight*). In *Chapter Six* I showed that for disabled young people at Explore, ‘growing-up’ did not necessitate breaking away from one’s parents, but rather, increasing networks of interdependency. We see from the above that disabled people’s conceptions of IL often had little to do with being alone, but were in fact about connectivity: “being able to live at home with my Mom, Dad and siblings as well as going to playschool” (Haraldsdóttir & Sigurðardttir, 2011, 8), or “being able to have my own family and a dog” (Haraldsdóttir & Sigurðardttir, 2011, 15). Appreciating ‘independence’ holistically can teach us other ways of thinking about becoming-independent-adult; helping to address research question three: what can disability and the lived-experiences of young disabled people teach us about youth?

I recorded the following after a dinner party at Freyja’s apartment:

“As much as I ‘get’ IL philosophies, they’re still not ones I’m used to living. We ate a lovely meal: but I wasn’t sure who the chef was to address my compliments. It felt weird that the assistants were serving us, clearing the table, doing the washing up. Should I offer to help? I didn’t, I just sat on my arse worrying.”

(Research diary, 13th February 2012)

Gibson (2006, 189) writes that the “binary division between independence/dependence has its roots in the assumption of the sovereign, autonomous self contained within a physical body – the division of self/other as individuated subjects”. According to Western thought, one cannot be ‘independent’ without a belief in the self-contained body. Rather than *autonomous*, there is something profoundly *connected* about not being able to find the person to thank in the situation above. I argued in *Chapter Four* that Deleuzoguattarian philosophies of becoming can help us think-through the liminal spaces that youth and disability inhabit:

“While, for example, Derrida said ‘no’ to one dominating pole of a binary in favour of another, Deleuze and Guattari say ‘yes’ to the possibilities between, within, across and below binaries”

(Goodley, 2007a, 114)

Deleuze and Guattari utilise the metaphor of a rhizome to represent between spaces. A rhizome is a non-hierarchical structure which resists binary divisions (Goodley & Roets, 2008). As rhizomes “always connect to something else” (Goodley, 2007a, 150), they cannot be rooted or contained. A rhizome cannot ‘be’, as it is forever ‘becoming’. To put the above scenario in Deleuzoguattarian terms then, the dinner party was profoundly rhizomatic. I am at Freyja’s dinner party, so I turn to Freyja as the chef and thank for a lovely meal. Yet, turning to Freyja, I see not an ending, but a point of connection to her assistant, whose hands have chopped my food, and are taking away my plate. Who do I thank in this situation? For some, the answer is obvious: the assistant who has performed the physical labour. My worries perhaps become clearer, however, when we consider critiques coming from ILMs around the difference between care and assistance:

“Historically within both medical literature and in real-world practice, disabled people have implicitly and explicitly been positioned as passive recipients of care enacted by omnipotent non-disabled professionals and burdened informal carers.”

(McLaughlin, 2006)

ILMs challenge paternalistic attitudes towards disabled people. According to ILMs, “assistance required should be identified and controlled by disabled individuals

themselves” (Gibson et al, 2009). This however means different things to different people. When Joe, a user of personal assistance was asked what it means to direct his own assistance, he responded:

“Basically I think what it is, is we use the attendants as our own hands. They do things that we can’t do. And basically you give them directions.”

(Gibson, 2009, 322)

Considering Joe’s words alongside IL philosophies in my own situation of not knowing who to thank, perhaps the answer is the opposite of that first assumed. I should thank Freyja. It is Freyja’s dinner party; she has provided the food, the company, the hospitality. Her assistants are merely being used as her “own hands”. Another disabled person, however, gave a different response when asked about their relationship with assistants:

“[Interviewer]: Do you see them [assistants] as people, or just hands and feet?

[User of personal assistance]: Oh yes, I see them as individuals with quirks, mannerisms, habits and personalities.”

(Gibson et al., 2009, 323)

There has been some conflict within feminist and CDS discussions of care and assistance (Kröger, 2009; McLaughlin, 2006). Feminist sociologists have highlighted the devalued gendered connotations of caring, considered the natural role of women in both paid and unpaid situations (Kröger, 2009). Yet, disability rights advocates have highlighted that these discussions fail to examine the role of the recipient of care (McLaughlin, 2006). Therefore, Othering disabled people as passive, dependent and burdensome (Morris, 1997). I was aware of IL philosophies at the dinner-party; awkwardly conscious of not using my own normative embodiment to position Freyja as a “passive recipient of [my] care” (McLaughlin, 2006). Yet, I was simultaneously uneasy about the rhizomatic dinner party. As my research diary confesses: as much as I ‘got’ the IL philosophies, they were not ones I was used to living. As ridiculous as it sounds on reflection, this all revolved around whether I should help wash-up! Although not the intention of the evening, the rhizomatic living of Embla and Freyja challenged me, once again (Slater, 2012a), to think-through the adulthood signifier of independence. The Deleuzoguattarian concepts of bodies without organs (BwO) helped me do this.

Deleuze and Guattari (1972) explain that Western thinking encourages us to conceptualise the world as bodies-as-organisms. A body-as-organism stands for ‘a whole’. A body-as-organism is assumed to take the form of a normative embodiment; the ‘able body’. It is made up of an organised and ordered system of various parts (organs) which rely upon each other for the whole to function. As a result, disabled people whose bodies do not comply with normative orderings of body-as-organism, are considered lacking Others (Goodley & Roets, 2008). A body-as-organism can be used to represent wider structures; how one thing is placed in relation to other things. Developmental discourse would have us believe, for example, that adulthood (*Figure 1*, p. 40) represents a ‘whole’ normative body-as-organism. Adults live autonomous lives as independent units, children and youth fail to do this, so they are lacking-adults (Burman, 2008b). Unquestioning assumptions of autonomous bodies-as-organisms root certain things and ways of being in certain places; i.e. children, youth and disabled people in positions of lack. Take the lacking positioning of children and disabled people alongside one-another, and we understand disabled people positioning as eternal children (Hall, 2011).

The metaphor of the BwO, however, helps us think differently. Rather than an ordered organism, a BwO is an unorganised assemblage. It is rhizomatic. It has no beginning and no end. A BwO is “sometimes a body or even a subject, but at other times, it is an institution or the universe” (Gibson, 2006, 190). BwOs are not static, knowable, separate bodies, but uncontained (and uncontainable) assemblages (Gibson, 2006). As *Chapter Four* outlines, some within CDS have utilised the BwOs to think-through the interconnected lives of disabled people (Gibson, 2006; Gibson, et al., 2012; Goodley, 2007a, 2007b; Shildrick, 2004, 2009; Slater, 2012a):

“Disabled people like all people, move in and out of multiple assemblages: human–machine assemblages of bodies, ventilators, wheelchairs; human–animal assemblages with pets and service animals and/or human–human assemblages with carers [sic].”

(Gibson, et al., 2012, 2/3)

A BwO is not static, but in constant flux, moving in and out of different assemblages. Gibson (2006) discusses this in relation to a man-dog assemblage (a blind man and his guide dog), a man-machine assemblage (a disabled man and his ventilator), and a woman-woman-man assemblage (an assistant assisting her disabled employer to have sex with a third person). These are all different states of the BwO. In all these relationships, she argues, subjectivity of the self is not abandoned, but accepted in a

constant state of becoming, dynamic and ever-changing. BwO conceptions are useful to the development of critically young spaces, considered in *Chapter Six*.

From her empirical work with men who use ventilators, Gibson (2006) argues that conceptualising the men as dependent on the ventilators, or the ventilators as being the men's access to independence is inadequate: rather she understand the men's relationships with the ventilator as (sometimes) a part of them. This was reflected in the quote above, when Jon said users of PAs "use the attendants as our own hands" (Gibson et al., 2009, 322). Whereas body-as-organism makes the disabled body, a body lacks, requiring the *addition* of supports, assistance and prosthesis (Goodley, 2009), BwO allows for these dependencies not as wholly separate but as things that are sometimes a part of the BwO, and at other times, not (Gibson, et al., 2012). Thinking about disabled people's embodied 'dependencies' through the metaphors of bodies-as-organisms and BwO "demonstrate[s] the possibilities in re-thinking the binaries of independent/dependent and self/other" (Gibson, 2006, 191).

Those using assistants are part of BwOs, immersed in networks of productive desire (Gibson, 2006; Shildrick, 2004). By disturbing the one-to-one relationship, the connectivity of a disabled body, Shildrick (2009) argues, unnerves us by reminding us of our own leakiness; our inability to inhabit a body-as-organism. Many of the people I spent time with in Reykjavik were involved with the ILC; they joked about other people's awkwardness around their assistants. During one of my first nights with the group, Aðalbjörg laughed about her sister's satirical outburst over Aðalbjörg's son's assistant: "I just don't know how to handle it! Can I talk to the assistant or not?!" The women all laughed, making jokes about "petting the assistant", and I remember awkwardly laughing along, but wanting some guidance (well, should I talk to her or not?!). According to Tedlock (2000, 455), ethnographers "are cross-dressers, outsiders wearing insiders clothes while gradually acquiring the language and behaviours that go with them", and this is how I felt in this scenario. This rhizomatic life was second-nature to those around me, and at first, I pretended that I too was comfortable with it. As time went on I did indeed learn the language and ways of be/coming of those around me. On the same night that I recorded the 'not knowing who to thank' scenario, I finally 'got it' when Embla and Freyja were joking about Freyja's dog, Nala, understanding IL philosophies more than most people:

“She gets IL!” Embla joked about Nala, prompting Freyja to expand. “Yeah, when Nala wants feeding she comes to me, then I ask one of my assistants to feed her, but she never goes to them first.” Finally, I got it! If when Freyja’s assistant brings me a coffee I want some milk, I just ask Freyja if she’s got any milk. I can offer to go get it myself, just like I would at anyone else’s house, or she can get it for me through her assistant.”

(Research diary, 13th February 2012)

We see here Freyja’s BwO in action; a concept it took me a while to grasp, but one Nala seemed to handle. For Nala, perhaps, it is not the assistants fetching her food, but a wider BwO which Freyja’s is part of feeding her. At Nala’s mealtime, the assistants are not separate from, but a part of Freyja. After the dog-feeding task is complete, however, the assistant-part of Freyja’s BwO becomes detached again. For Freyja, and those involved in the ILM, ‘independence’ comes about through interconnectedness of BwOs.

On a different occasion Freyja told me the following story:

“I had an interview to work with children at a nursery. As soon as I entered the room I saw how surprised the interviewer was. She didn’t even try to hide it. The first thing she said was, “so I see you’re disabled... what would *you* do here?””

(My version of Freyja’s story, research diary, 16th February 2011)

The interviewer reduces Freyja to body-as-organism. As a disabled person Freyja challenges normative assumptions of whole autonomous bodies-as-organisms that carry out a job on their own (Goodley & Roets, 2008). “So I see you’re disabled”, is an accusation: why did *you* bother to apply for this job? Freyja is conceptualised as an unorganised, lacking, body-as-organism. It is assumed she is unable to carry out the roles required in the job specification. Such a conceptualisation maintains traditional assumptions of disability. Freyja is disabled and therefore unproductive (Barton, 1993). Yet Freyja contests this:

“Well, I’d do what the job specification requires of me: I’d look after the children. “But how?” the interviewer asked. She just couldn’t get her head around a woman with a physical impairment working with children. I’d worked in a nursery before, it wasn’t that difficult to understand: my assistants did the physical stuff I couldn’t, while I did the more emotional side of it. To kids, it just isn’t a problem.”

(My version of Freyja’s story, research diary, 16th February 2011)

Freyja does not abandon the self, but neither does she consider her assistants wholly separate to her. They are part of the constitution of her BwO: at times a part of her BwO. To employ Freyja is to employ Freyja's BwO. Through her assemblage, Freyja's BwO would complete the tasks required. Freyja expanded upon the final statement, telling me that kids 'get' the philosophies of IL more easily than most:

"I was dropping my friend's little boy with his grandma after taking him to the zoo this one time and his grandma asked him: "who went to the zoo with you?" "Just Freyja", he said. She looked a bit puzzled. "Really? Just Freyja?" "Yeah, just Freyja" The grandma pointed to my assistant: "didn't she go with you?" "Oh, well, she was there, but she wasn't with us, I just went with Freyja".

(My version of Freyja's story, research diary, 25th February 2012)

The boy Freyja took to the zoo and Nala the dog understand the relationship between Freyja and her assistants similarly. Yes, Freyja's assistant was there, but it was only him and Freyja on the trip - Freyja's BwO seems so common-sense that it is hidden. Yet the woman at the nursery, the grandma and myself earlier, learned in the entrenched ways of Western individualism, could not understand this: "but how are *you* going to do the job?"; "of course somebody was at the zoo with you – there she is!"; "who do I thank for this meal?"

Research question three asks what disability and the lived-experiences of young disabled people can teach us about youth. The above helps us to rethink youth as becoming-independent-adult. Hughes (2001) highlights that critiquing notions of independence has been at the crux of disability activism. Although 'independence' is part of the dialogue of ILMs, it seems for those involved it represents something different to what has become its common-sense usage. Murray (2002, 21) reported that for her young disabled participants independence was about having the chance to build relationships, and participate in activities alongside peers. Requiring support was not a negative aspect of this, "on the contrary, the presence of appropriate support allowed for new adventures to take place". Fighting for their right to independence, young disabled people expand our notions of independence. Disabled youth fighting to become-independent-adults is different to Western conceptualisations of doing things on your own. For Freyja, "independent living means being able to make my own decisions, create my own lifestyle so I can be fully myself" (Freyja cited in Haraldsdóttir & Sigurðardóttir, 2011, 28). To put

this in Deleuzoguattarian terms, to allow each to be fully oneself, is to allow for becoming in a multiplicity of ways. Similarly to the lessons of *Chapter Six*, Youth as Active, rethought with our new conceptualisation of independence, is about expanding, dynamic and interconnected networks of interdependence. These allow for new experiences (Murray, 2002) as part of a continual becoming of life (Shildrick, 2009).

Arguing through ‘reasonable’ and normative language of independence, particularly as it relates to consumerist discourses of production and consumption (the right to work/buy) allows disabled youth to live, what I have conceptualised as, their rhizomatic lives. Through mimicking normative adulthood, they are mocking normative adulthood. However, I noted in *Chapter Four* that mimicry can be “a strategy of [colonial] exclusion through inclusion that purports to accept the ‘good native’ all the better to exclude and denounce the majority ‘bad natives’” (Childs & Williams, 1997, 129). Although for some, and I would use Embla and Freyja as my examples here, fighting through normative discourse has allowed them to live what I shared at the beginning of this chapter are lives as ‘strong’, ‘independent’ women, other disabled youth are not in places which allow them this mockery. The Fergusons (2001) for example, may worry that this mimicry/mockery is not an options for those with ‘profound’ or intellectual impairments. It is to these concerns I now turn.

Autonomy, the personal pronoun and people with labels of intellectual impairment

ILMs reposition assistant-disabled person relationships. Whereas traditionally the relationship of ‘carer-cared for’ is one where the carer holds the power, ILMs realign this to ‘employed-employer’, where the disabled person is in control (McLaughlin, 2006; Morris, 1997):

“The user is seen as an autonomous individual and the relationship between the receiver of services and the care worker is regarded as that found in ordinary employment, where the care worker executes the user’s ‘orders’.”

(Askheim, 2003, 328)

This relationship is different to Deleuzoguattarian rhizomatic networks as whereas the rhizome “describes and prescribes non-hierarchical networks” (Goodley, 2007b, 149), ILMs explicitly advocate for hierarchical structures, which disabled people control

(Gibson et al., 2009). A concern around people with intellectual impairments and their in/exclusion from ILMs is that said people may not be in positions to implement the level of user control required as an employer. Therefore, in order to incorporate people with intellectual impairments, the principle of user control is compromised (Askheim, 2003). Furthermore, there are arguably greater power differentials between people with intellectual impairments and their often non-disabled assistants. Therefore, the relative power can be more easily undermined. During my time in Iceland 26-year-old Arnar, a board member of Reykjavik's ILC with the label of intellectual impairment and strong views on independence, gave a presentation about his independent life with the support of his assistant.

“Arnar stands by the microphone, next to his assistant. The *PowerPoint* behind him shows pictures from his life. Arnar's name is on the programme: it is his presentation about him being an independent man, yet his assistant does much of the 'talking'. Occasionally she turns to him for clarification, at which point he leans in to the microphone, and shouts a defiant 'já' (yes) or 'ekki' (no). He (through his assistant) explains that he used to live in a residential home. “Did you like it there?” his assistant asks him, “ekki!” Arnar is sure he prefers his life today, living in his own place and hiring his own assistants which enable him to live independently. He tells us about this life where, with assistance, he does his shopping, cooks his meals, goes to work, and so on.”

(Research diary, 14th March 2012)

Like Freyja, despite what others may see as his dependencies on his assistants, Arnar considers his life one of independence. He demonstrates through his presentation the Arnar-assistant BwO 'working in line' with IL philosophies. Yet, later I record the following:

“A member of the audience asks Arnar a question: “do you have any brothers?” Arnar replies, yes, he does. The assistant seems hesitant, but leans towards the microphone, “no, he doesn't”. Although non-disabled, as the mother of a disabled son, Arnar's assistant is a board member of the ILC and good friends with the rest of the board, who are sitting beside me. She looks guiltily at them before saying: “I shouldn't have said that, I just broke the first rule of assistance.””

(Research diary, 14th March 2012)

The above demonstrates worries around IL and people with intellectual impairments. For disabled people involved in ILMs negotiating the relationship between themselves and their assistant is vital. Arnar did not speak back to his assistant, and the conference

moved on, I speculate, with no long-term negative effect on Arnar's life. Yet, the concern is that the scenario could happen in situations with greater impact. For ILMs the assistant is "expected to be a detached "tool"" (Gibson, 2006, 192) which the disabled person controls. Yet, for Deleuze and Guattari, a BwO is rhizomatic. Relationships are in flux, and both parts of the disabled person-assistant relationship maintain an element of the self. Due to this, "despite knowing her role, [Arnar's assistant] experiences a leaking of her identity" (Gibson, 2006, 192). Believing that Arnar does not have a brother, Arnar's assistant steps in to correct Arnar, restricting the story he has to tell. For Deleuze and Guattari, the effects of assemblages can be both enabling and disabling (Gibson et al., 2012). For people critical of ILMs, the potential disabling effects of assistant-disabled person with intellectual impairment assemblages are problematic:

"The relationship between [disabled people] and [their assistants] are complex sites of engagement constituted through interpersonal, social and political forces that can have enabling or disabling effects for both."

(Gibson et al., 2009, 317)

The same afternoon, however, there was a presentation by a representative from a Swedish ILC called JAG, whose members all have "multiple, severe disabilities including some kind of intellectual disability" (Tengström, no date). In Swedish, the initials JAG stand for Equality, Assistance and Inclusion, and the word 'JAG' itself means 'I'. Deleuze and Guattari ask us to question the personal pronoun: without a whole and autonomous self, who is the 'I' (Slater, 2012a)? Like 'independence', focusing on 'I' seems out of balance with Deleuzoguattarian philosophies. If we look back at the history of institutionalisation, however, we see why defining yourself as an individual subject (an 'I') could be so important to people with the label of intellectual impairment. As Wolfenberger wrote in 1969:

"Retardates [sic] are particularly apt to be unconsciously perceived or even consciously labelled as subhuman, as animal-like, or even as "vegetables" or "vegetative.""

(Wolfenberger, 1969, 16-17)

Or, as Shildrick (2004) puts it, "disability touches on a far more entrenched understanding of what it is to be a subject at all". Research question one asks what dangers young disabled people face if normative discourse remains unquestioned. Considering disabled people as subhuman, denies their right to existence. Overboe (2007) reminds us of the continuing presence of this subhuman label. In *Chapter Eight I*

further consider the consequences of this in relation to gender and sexuality: disabled young people are not only threatened with institutionalisation, but disabled people's devalued status reinforcing a continued eugenic drive which threatens young disabled women (Hall, 2011; Roets, Adams, & Hove, 2006; Tilley, Walmsley, Earle, & Atkinson, 2012).

As the speaker from JAG went on, she described what 'I' means to JAG members: "not we, not me, but I. Not *we* are doing this together; not *he* is doing this *with me*; but *I* am doing this with assistance". JAG believes that every person can demonstrate self-determination; it is a matter of understanding particular forms of communication. "Self-determination can [...] be regarded as an act of interdependence, where one individual works with others to derive and meet goals, and be autonomous, active members of their community" (Kelm, 2009, 118). The JAG model works through a layering system. The disabled person has a 'legal proxy', somebody who knows them well, can support their right to 'self-determination' and understands their methods of communication. Although, as I discussed in the previous chapter, parents have been seen a barrier to young disabled people's independence (McLaughlin, 2006; Ryan & Runswick-Cole, 2008), JAG "emphasise that the parents are the persons best capable of knowing what their children mean and want, since no one else could be more competent in interpreting their often complicated signals of communication" (Askheim, 2003 327). Although I find the all-encompassing nature of this statement potentially problematic, the fact remains that JAG members are routinely represented by their parents. Parents are seen as potential routes rather than barriers to independence for disabled people (Ryan & Runswick-Cole, 2008).

The next layer is the 'service guarantor' who directly supervises and manages the day-to-day activities of the assistants:

"The service guarantor is a person who knows the user well and who has the task to secure that the user has the control over the arrangement. A part of it is the responsibility to teach the assistants how to interpret the user's signals of communication. In the first period after the assistants have been employed the service guarantor therefore works together with them until the assistants have got to know the user."

(Askheim, 2003, 336)

Finally there are the assistants themselves. These 'layers' make the 'I' of JAG profoundly connected. As Gibson reminds us, a BwO is "sometimes a body or even a

subject, but at other times, it is an institution or the universe” (Gibson, 2006, 190). The BwO JAG members act within illustrates even more clearly than Freyja’s situation the uncontained and uncontainable nature of assemblages (Gibson, 2006). Like at Freyja’s rhizomatic dinner party, sometimes the assistant-disabled person acts as a BwO. However, sometimes the service guarantor may also be part of the assemblage. Later that day the assemblage may be different again, including, perhaps, a parent and/or a legal proxy. Of course, machines may also be part of these assemblages: wheelchairs, prosthesis, ventilators. In fact, the institution of JAG itself, or indeed, wider politics of ILMs, can be conceptualised as larger BwOs, within which infinite smaller assemblages simultaneously act:

“[P]rocesses of “becoming” [...] resist finalizing individuals as fixed, contained and separate, and instead explore actions, productions and possibilities afforded through the movements in and out of human-machine assemblages”

(Gibson et al., 2012, 2)

For JAG, the connectivity of ‘I’ was an uncontained and uncontainable assemblage which was both a result of, and enabled the formation of further assemblages. The connected ‘I’ enabled JAG members to ‘do things’: to be rhizomatic, to connect with others, to build relationships, to flow, to *become*. Shildrick (2009) tells us it is not that disabled people are unique in their interconnected lives, we are all dependent on different things over time and space, flowing in and out of various assemblages; it is just for some of us, it is easy to hide. Looked at through Deleuzoguattarian lenses, the interconnected and interdependent lives of JAG members show JAG members to be “no different from any other person”. Furthermore, this interconnectivity is something to celebrate:

“The disabled woman who needs an assistant or carer to help her prepare for a sexual encounter - be it in terms of dressing appropriately, negotiating toilet facilities, or requiring direct physical support to achieve a comfortable sexual position - is not different in kind from other women, but only engaged more overtly in just those networks that Deleuze and Guattari might characterise as desiring production.”

(Shildrick, 2004)

Like we saw earlier as ILMs reconceptualised ‘independence’, JAG members use ‘I’ differently to the Western conceptualisation of an individual unit doing things alone (Gibson, 2006). For those involved in ILMs, having assistance does not get in the way of independence or being an ‘I’. The speaker from JAG stressed that she could not offer us

a definite model of IL, as there was no ‘one-size-fits-all’ approach to IL (the assemblages are uncontainable). JAG’s fight to be an ‘I’, therefore, are not about ‘sameness’ but a respect for multiplicities of different ways of living. The movement embraces BwOs, and within this solidarity politics of disability there is a drive to make these different assemblages as enabling as possible (Gibson et al., 2009; 2012).

Discussion

I began this chapter by outlining how, like literature cited in *Chapter Two*, young disabled people at YF used normative equality-based arguments to assert themselves within discourses of youth as becoming-adult. I therefore worried that my critique of adulthood contradicted strives of these young people. It was okay for me to shout about how great it was that disability did not fit into normative conceptions of adulthood, but these were discourses young disabled people wanted to be a part of. Yet, through writing this chapter I have made a number of arguments.

Research question one asks what dangers young disabled people face if normative discourse remains unquestioned. We have seen that young disabled people felt the need to assert themselves as normative becoming-adults. Through these battles they challenged rhetoric of disability as difference. This helped to resist internalising psycho-emotional disablism (Reeve, 2002), and ward off dangers of being made part of a disposable population (Giroux, 2009). I have argued, however, that fighting for their place within normative discourse was not so much of a desire, but a mode of survival (Ferguson & Ferguson, 2001). Like the Fergusons (2001) I continue to worry that in having to strive to be the normative, young disabled people are being denied other things; i.e. the opportunity to be young and be/come as disabled people. Therefore, to be an ally, whilst acknowledging the timely and important political battles of my disabled peers, I feel my job as a CDS researcher is different. To simultaneously challenge conceptions of youth and adulthood, by developing, what I outlined in *Chapter Six* are arenas in which to be critically young.

Young disabled people help me in this. As I outlined in *Chapter Five*, critically young spaces must be vigilant to adultism and ableism; challenging both normative conceptions of disability, and of youth and adulthood. Thus, it is important to think-through research questions three and four together: what can disability and the lived-experiences of young disabled people teach us about youth? And what can youth and the lived-experiences of

young disabled people teach us about disability? I have argued that when young disabled people contest that disabled people are dependent, passive and burdensome, they are mocking adulthood. Fighting through rhetoric of normative adulthood independence, allows disabled youth the time and space to live 'rhizomatic' lives which crip the meaning of the very words they are employing. Young disabled people teach us that Youth as Active is about becoming; however, it is not about becoming-adult in its normative, ableist sense. Becoming-adult is not about doing things alone, but dynamic and expanding interdependent networks that increase experiential opportunities (Murray, 2002). We once again see disabled youth teaching us about an on-going, dynamic process of becoming-in-the-world together (Shildrick, 2009). In the final chapter I continue to think about youth and adulthood, but this time gender becomes a focus, as I ask what disabled girls can teach us about becoming-women.

Chapter Eight

Disabled Youth, Gender and Sexuality: Crippling Youth for Sale

Introduction

Chapter Three explains that gendered discourses of Youth for Sale tie youth to the ‘body beautiful’ (Priestley, 2003). In *Chapter Seven* I shared Freyja’s argument that disabled women should have the same right to buy high-heeled shoes as non-disabled women. Through this story, I touched upon discussions of gender and sexuality. We saw that for young disabled people ‘independence’ is about more than doing things alone. For Embla independent living (IL) means “being able to be a woman” (Embla cited in Haraldsdóttir & Sigurðardóttir, 2011, 7). Young disabled people’s relationships with and thoughts around disability, gender and sexuality are the focus of this chapter.

I begin by extending arguments from *Chapter Three*, considering young disabled people’s positioning within discourses of gender and sexuality. I highlight the lived-realities of exclusion from normative discourse for disabled youth. Thus I address research question one: what dangers do young disabled people face if normative discourse remains unquestioned? Like in previous chapters, however, I find “disabled people are not simply passive victims of [...dis/ablism] - many exercise agency and resist” (Reeve, 2002, 493). I share the stories of disabled youth challenging assumptions of asexuality which surround disability. Moreover, I posed in *Chapter Three* that although the beauty and related industries have abstracted youth into a commodified health-and-beauty thing which excludes those differently embodied, they are not the sole producer of ‘youth’. I argue that disabled youth can mock normative conceptions of womanhood, and through this create their own youth-thing, inclusive to their own ways of being/becoming. I therefore also address research questions three and four in respect to gender, sexuality and womanhood: what can youth and the lived-experiences of young disabled people teach us about disability? And what can disability and the lived-experiences of young disabled people teach us about youth?

Thinking about sexuality, gender and the body with disabled youth

Chapter Three taught us the gendered nature of Youth for Sale. There is a particular requirement for women to hold onto the ‘sexy signifiers’ we equate with youth (Heiss, 2011). Furthermore, Youth for Sale is closely tied to normative discourses of sexuality. Disabled people, however, are rarely included in normative discussions of sexuality, as Liddiard writes:

“Our [disabled people’s] bodies and identities are routinely cast with the sexual stereotypes of asexuality [...] or sexually inadequacy. Rather confusingly, some of us can also be seen as sexually deviant or “hypersexual” and others of us are assumed only to be sexual victims or objects of fetish.”

(Liddiard, 2012)

Shildrick (2009) argues that a disabled body that demands intercorporeality through a requirement of assistance and prosthetics evokes anxiety as it disturbs the self/Other relation. We are taught from childhood that sexuality should be the most private of pursuits. Discourses of sexuality epitomising the Western drive for individualism. When disability is thought of in relation to sexuality, therefore, anxiety is heightened (Shildrick, 2009).

Youth and sexuality also hold troublesome relationships. In *Chapter Four* I argued that youth’s straddling of the space between child and adult leaves us unsure how to treat young people. Children are wrongfully presumed asexual. Therefore, there is little language of childhood sexuality. Nevertheless there are clear rules, i.e. children and sexuality do not mix (Nodelman, 1992; Rose, 1984). Youth, however, confuses things. Wyn and White (2000, 165) highlight the contradiction of the youthful body, that is, on the one hand, “subject to the requirements of proper dress and discipline” but, on the other, “highly sexualised”. Although there is a legal age of sexual consent, the way we think of and portray young people in relation to sexuality is surrounded in contradiction. Subjecting youth to “proper dress and discipline” (Wyn and White, 2000, 165) renders them passive. Similarly, positioning of disabled people as asexual eternal children leaves disabled youth in the realms of passivity. However, an image of youth as “highly sexualised” (Wyn and White, 2000, 165) bridges Youth as Active and Youth for Sale. Young people are exposed to highly sexualised images of their peers (Youth for Sale) whilst simultaneously being scorned upon for their sexual deviance (Youth as Active).

Arguably, the discourse of hypersexuality which surrounds disability similarly demonises disabled young people as (over)active youth. Disability, however, is rarely equated with the highly sexualised images of youth (Hughes, et al., 2005). Disabled young people are therefore excluded from discourses of Youth for Sale (see *Chapter Three*).

A recent participatory study with young disabled people highlights some of the complexities around disability and sexuality for disabled youth:

“In a discussion about sex education at school, the one group member who had attended a mainstream school said they had been shown videos of very difficult births in order to scare girls off having sex and getting pregnant. Those who had attended special schools were amazed at this. In special schools, they said, teachers ‘would have been too frightened to talk about sex or relationships’. One of the young women in the group had strong views on this issue. She said it was typical of the way special schools treated students that it simply would not occur to them that a girl with a disability might get pregnant before leaving school.

“They couldn’t let you do that [talk about having sex] because the cotton wool would be broken. The cotton wool that they wrap you up in the day you start. By the time you leave the cotton wool has pretty much smothered you”.

(Horgan, 2003, 104-105)

The quote exemplifies complexities around youth, disability and sexuality. In the ‘special school’ disabled young people were presumed to be passive youth; incapable of having sex and getting pregnant, so they were told nothing. In the ‘mainstream school’, however, young people were considered dangerously active: sex and pregnancy was considered a risk. They were taught that having sex and getting pregnant are bad and painful experiences, to scare them from both practices. The different approaches to talking to disabled and non-disabled young people about sexuality have been noted by Morris, she writes:

“Sex and sexuality figure as important issues in the transition to adulthood for non-disabled young people but adults do not always recognise that disabled young people will have the same sexual feelings of others of their age. This can result in a lack of information and inappropriate advice, creating confusion for young people, their parents and carers”

(Morris, 2002, 7)

Yet, neither scenario in Horgan's (2003) study seems helpful. It is not acknowledged that teenagers can and do make good parents. Young people are not taught that sex is can be fun and pleasurable. There is no attempt to expand notions of sex and sexuality outside of sex being about penis-in-vagina intercourse that leads to babies (a bad thing).

Research question one asks, what dangers do young disabled people face if normative discourse remains unquestioned? Here we see dangers inherent to both discourses of Youth as Passive and Youth as Active in relation to sexuality. Attempts made to pacify those who are considered active youth through misinformation, scaremongering and demonization, whilst those considered passive, to paraphrase Horgan's (2003, 105) participant, are 'wrapped up in cotton wool'.

My participants agreed with the young woman in Horgan's (2003) study that they are often considered in relation to discourses of asexuality. I recorded to following after chatting to Molly at YF:

"Molly is a swimmer, and wanted the contraceptive pill so her periods were predictable and would not get in the way of her swimming. Her doctor was okay with this. Nevertheless, there are questions doctors ask when requesting the pill, one being whether the woman is 'sexually active'. Surely, it is expected that the girl is the one to blush and mumble something, not the medically trained bodies-are-science doctor. However, Molly laughed as she told me of the doctor's discomfort in asking this question. As a girl with a physical impairment, requesting the pill on sporting-grounds, the doctors phrasing went: "erm... I'm really sorry but I've, erm, got to ask you this... and I know, well, of course you're not, I mean, I know you're not... sexually active... are you?" Molly, joked that she should have replied: "well, I'm shagging a different girl every night, if that's what you mean?"

(Research diary, 23rd November 2011, after first futures workshop, YF)

Molly laughed, but this conversation was deemed a 'laugh or cry' scenario. Although Molly made light of it, the assumption the doctor is making above, that disabled people are not sexual beings, is a mark of disability oppression, tied intrinsically with the positioning of disabled people as eternal children (Hall, 2011). Hall (2011) uses the case of Ashley X, or "*The Pillow Angel*" to illustrate this point.

Ashley X was nine-years-old when, in 2007, news broke that she had three years earlier been subject to medical intervention to stop her growth and development. Treatment included hysterectomy, the removal of breast buds, to prohibit growth of her breasts, and high doses of oestrogen to stop growth (Edwards, 2008). Those justifying the surgery

argued that Ashley's motor and cognitive skills would remain like those of a three-month-old baby. Therefore, ensuring Ashley's body never acquired the signs of 'womanhood' would prevent her future discomfort, and make it easier for her parents to take care of her (Hall, 2011, 1). As headlines broke, Ashley's parents were criticised. It was posed that their actions were "grotesque" (cited in Hall, 2011, 5), to which they replied: "'the prospect of having a full-grown fertile woman endowed with the mind of a baby' is what is really grotesque" (cited in Hall, 2011, 5). Furthermore, they wrote on an online blog: "we call her our Pillow Angel because she's so sweet and stays right where we place her, usually on a pillow" (cited in Hall, 2011, 4). As Hall points out:

"Ashley's parents call her their "Pillow Angel" because she stays just where they put her. In fact, their decision to prevent sexual development and growth ensures that Ashley will stay just where they want her to be, literally their little girl for the rest of her life."

(Hall, 2011, 4)

I do not find it helpful to lay individual blame with Ashley's parents. However, Ashley's situation highlights how implicit cultural conceptions of what it is to be 'woman' exclude disabled women from 'womanhood' (Hall, 2011). Furthermore, Ashley's case exemplifies how dangerous relationships posit disabled people's bodies as a) childlike (Johnson, et al., 2010), b) asexual (Garland-Thomson, 2002; Liddiard, 2012), and c) the property of others, to be subject to intervention (Barton, 1993; McCarthy, 1998). Ashley's story illustrates the potential consequences of positioning young disabled women outside discourses of normative sexuality.

A similar analysis can be made of a story co-written by Roets, Adams and Van Hove (2006). The article tells us about one of the authors, Marie Adams, a woman with the label of intellectual impairment, and the battles she and her allies faced when sterilisation was, in 2002, "imposed on Marie as an absolute, ineluctable necessity" (167). As the authors explain:

"The professionals threatened that if she [Marie] or her mother refused to sign the consent form [consenting to Marie's sterilisation], they would declare her to be a 'person under age in an extended way due to moderate mental retardation'. This would involve forgoing the right to her own money and to make her own decisions."

(Roets, et al., 2006, 170)

Again, we see disability linked with non-normative sexuality and a child-like state of being. Declared 'sexually unfit', Marie is also deemed incapable of making other decisions. Conversely, although (failed) attempts were made to make Marie passive in the process of sterilisation, this story not only illustrates discourse of asexuality surrounding disability, but also hypersexuality, which more readily sits with the construct of Youth as Active. Like we saw in the discussions between young people in Horgan's (2003) study, there was no attempt to engage Marie in informed discussions of sex and sexuality. Rather, attempts are made to scare her into agreeing to sterilisation:

"Marie was advised that by going ahead with the sterilization she was never going to have trouble with 'shady blokes who want to rape you' any more. This was, and is until today, one of her major fears:

(Marie) In Ghent, there was a shady bloke who wanted to rape me. He had been dragging me along. Well, I am terrified, to get pregnant and so on. He got me in the bushes, in the park. I was thrashing about, and yelling at him, 'let me go, you rotten bastard'. But they won't believe me at all! That gynaecologist said, that isn't possible anyway. I'm worried sick, to get pregnant from that bloke. But she says I go beyond my limits. And that if she will do that intervention, that it won't happen ever again. That she will make the decision about what's happening with me."

(Roets, et al., 2006, 170)

With support from her self-advocacy group, mother and academic advocates, Marie resisted sterilisation. However the sterilisation of disabled young women is not a historical phenomenon (Roets et al., 2006). Marie's fight took place in Belgium in 2002. Furthermore, although the occurrence of surgical sterilisation may have decreased, young women with the label of intellectual impairment are often given long-term contraception, without explanation, their knowledge or consent (Chamberlain, Rauh, Passer, McGrath, & Burket, 1984; McCarthy, 1998; Tilley, et al., 2012). The justification often used is that sterilisation/long-term contraception prevents abuse (McCarthy, 1993). Such arguments not only remove blame from violent perpetrators and place responsibility upon women, but *increase* the likelihood of abuse:

"Much abuse is perpetrated by male family and staff members, these men would presumably know that as detection through pregnancy will not occur, their chances of being caught and identified are reduced"

(McCarthy, 1993, 571)

I am not here denying young disabled women's right to contraception (or hysterectomy). Rather, I am arguing that it should be an informed, rather than an enforced decision. The above stories highlight that discourses of vulnerability and resultant paternalism readily attached to disability and Youth as Passive, do little to protect young disabled people. Rather, entwined discourses of disabled people as asexual, hypersexual, sexual victims and objects of fetish (Liddiard, 2012) work together to devalue disabled people, legitimise surgical or other sterilising interventions, and foster abuse.

Considering youth as incomplete-adult is complex, iterative and dependent on intersectional identities. Complicated denials of disabled people's right to sexuality work to sustain the infantilisation of disabled people. This simultaneously denies disabled young women a place in normative discourses of girl as becoming-woman. As womanhood is strongly tied in with reproduction and childbearing/rearing, the expectation on non-disabled young women is to grow up and become mothers (Letherby, 2002). Yet, there is both a historical and continuing eugenic drive for disabled young women to remain childless (Tilley, et al., 2012). As detailed in *Chapter Five*, I spent much time during in Iceland discussing the complexities of gender, sexuality and disability with Embla and Freyja. As a result of our conversations we decided to co-write a paper, an excerpt from the abstract goes as follows:

“Jenny: when I was a teenager well-meaning relatives began to ask, “So do you have a boyfriend?” As time went on, with no sign of the elusive male other-half, the question became, “do you have a boyfriend... yet?”; “when will you get a boyfriend?” Now, the question seems to have dropped, I guess to be replaced with whispers, “will she ever get a boyfriend?”, “is she... gay?”

Freyja: My story is quite different, but the feelings were the same. As a disabled teenager, my well-meaning relatives made an effort not to ask: I was hoping for the question, “do you have a boyfriend?”, but it never came. Yet at the same time, I didn't want the question: it embarrassed me – as a disabled person, did I have the right to that question? Nowadays, my cousins are always asked, “When are you going to have kids?”, again, it's not a question I'm given.”

(Data generated through cowriting Slater, et al., 2012)

Different expectations are placed upon different young people, dependent upon intersectional identities. It has been problematically noted that expectations of young disabled people are ‘low’ (Morris, 2002; Priestley, 2003). For me, however, the notions of ‘low’ and ‘high’ expectation are unhelpful, as they continue to prioritise certain ways

of 'doing adulthood' over others. Rather than say disabled young people are denied expectation per se, therefore, I find it more useful consider different axes of normative expectation. As the above shows, whereas the expectation on me, as a non-disabled young woman is to grow-up, find a male partner and have children (Gordon & Lahelma, 2002), the expectation on Freyja, as a disabled young woman is the opposite: to remain an eternal child, asexual and childless (Hall, 2011). Furthermore, Freyja's words above, "as a disabled person, did I have the right to that question [of a future coupled status]?" alert us to dangers of internalising the prejudice that disabled people are asexual (Reeve, 2002).

The normative expectation on non-disabled young women to have children is illustrated in Goltz' (2009) study of queer people's notions of the future (in which disability is not mentioned). Goltz found that parents were less concerned about their daughters' same gender relationships when assured they still planned to have children. One participant impersonates her mother's reaction to her 'coming out': "Love whoever you want. I don't give a shit. Just have babies" (Goltz, 2009, 574). However, as a gay disabled young woman, Embla's experiences were different:

"...just for the record, when you're gay, you're never asked if you'll have kids. With disability comes the expectation of asexuality... so not being straight never comes into the equation. Disabled lesbians... is there such a thing?"

(Embla, data generating through cowriting, Slater, et al., 2012)

The final question Embla asks: "disabled lesbians... is there such a thing?" refers to research done by Skjaldardóttir (2012), a friend of Embla and Freyja. When doing research into society's attitudes towards disabled lesbians for her BA thesis, Skjaldardóttir was not surprised to find that there was little support for gay disabled women, she was, however, shocked at the response of many of her friends when she told them the subject of her research: "disabled lesbians... is there such a thing?" It seemed the expectation of asexuality meant the question of disabled people being gay, was a step too far. Although participants in Goltz's (2009) study were able to persuade those around them that as queer young women they could still adopt the mothering role of normative womanhood, as Embla points out, for gay disabled young women, the task of placing themselves within normative discourses of womanhood was difficult. It seems that disabled people's movements have further to go than LGBT movements in positioning themselves within normative roles of gender, sexuality and the family. Therefore, we

further understand why disabled young women like Freyja and Embla may feel it important to posit disabled women as “no different from any other person” (Colin at YF) through, for example, Freyja’s story of high-heeled shoes shared in *Chapter Seven*.

A positioning outside of ‘womanhood’ and an expectation of asexuality, however, did not mean the young women I spoke to were immune from pressures to conform to idealised body images women are routinely presented with (McCarthy, 1998). Time I spent with two sisters, Dr. Lelo and Princess Hanna, at Explore illustrate this. I begin with a pen portrait, sketched after my initial meeting with the young women:

“Lelo and Hanna didn’t just walk in, they waltzed in. They’ve got style! 13-year-old Lelo’s ‘look’ sits something between Lady Gaga and Lily Allen. She pulled off her leopard print hat to reveal an asymmetrical haircut, working with her denim shorts and mismatched Converse trainers. This girl’s cool! Far too cool for the likes of me: she wasn’t particularly interested in talking, wanting to knuckle down and get on with things. 16-year-old Hanna, Lelo’s older sister, was more up for a chat. She tells me that she and Lelo share a bedroom, and they’ve got different ideas about how it should look. The family are moving to London soon, where she’ll have her own room which she and her Mum will paint pink. I get the impression of a feminist ‘girls-together’ family. Four sisters and Mum (who stays for the session), no mention of Dad. Both girls have the label of intellectual impairment. Unlike Lelo, Hanna’s impairment is visible. Hanna does the moody teenager thing incredibly well! It seems in her cool arty family she’s already done everything I had on offer. Eventually, I persuaded her to have a look at the ‘*Report from the Future*’ (*Appendix One*) and think about where she wants to take her ideas from there.”

(Research diary, 7th December 2012, Explore)

I sat with the girls while they filled in their initial ‘Report from the Future’ booklet (*Appendix One*). My research diary continues:

“Lelo chose the age of her time travelling avatar to be “10, 954 (but don’t have wrinkles)”. Lelo was aiming this tease at her Mum, whom sat across the table from her. Later Hanna got to the question which asked her to describe what she saw stepping out of her time machine. She drew a woman in a red dress, heels and a crown, with exaggerated red lipstick, large circles of blusher and big eyes with predominant eye-lashes (*Figure 25*). I asked Hanna if the picture was of her, the time traveller, or someone that lived in the future world. I was shocked when she told me it could never be her because she was too “fat and ugly”, but this drawing was what women were meant to look like.”

(Research diary, 7th December 2012, Explore)



Figure 25: Princess Hanna 'Report from the Future': "You have landed in your future world: what do you see?"

Youth for Sale makes youth synonymous with the 'body beautiful' (Heiss, 2011; Priestley, 2003). My conversations with Lelo and Hanna show us the complex workings of Youth for Sale with discourses of aging and femininity, and the impact on those whom feel excluded from them. When Lelo quips that she would be very old, but have no wrinkles, she demonstrates her awareness of the expectation on women to retain a 'youthful' body (Featherstone, 1982). I argued in *Chapter Three* that a youthful body has become naturalised to a normative standard of the female body (Garland-Thomson, 2002). I worried about this for all girls and young women, however, as disability acts "as a synecdoche for all forms that culture deems non-normative" (Garland-Thomson, 2002, 4), I speculated that feelings may be particularly acute for disabled young women. As the vignette goes on, we see psycho-emotional dangers of Youth for Sale to young disabled people. Psycho-emotional disablism affects what disabled people can *be*, rather than just what they can *do* (Reeve, 2002). Hanna's feelings that she is "too fat and ugly" to be what women should *be* worryingly exemplifies internalising the oppression of psycho-emotional disablism (Reeve, 2002).

Although perhaps harder to 'see' than structural disablism, psycho-emotional disablism can have violent consequences (Reeve, 2002). Exploring the self-esteem of women with physical impairments, Hassouneh-Phillips and McNeff found:

“Women with high degrees of physical impairment are more likely to perceive themselves as sexually inadequate and unattractive than women with mild impairment. These negative perceptions, when combined with a strong desire to be partnered, increased women’s vulnerability to getting into and staying in abusive relationships over time.”

(Hassouneh-Phillips & McNeff, 2005, 227)

Challenging the objectification of women’s bodies is, of course, important for all young women. However, the above statement alerts us that this is perhaps particularly important for those considered to be embodied furthest from the (pseudo)norm.

McCarthy (1998) considers bodily satisfaction for women with the label of intellectual impairment. She highlights the false assumption that women with intellectual impairment are in some way 'blessed' to not feel pressured to conform to society’s conceptions of normalcy. This is in itself an example of aversive disablism (Deal, 2007), positioning disabled people not only passive, but 'not quite human'; a dangerous positioning we have seen used to justify abuse (Hassouneh-Phillips & McNeff, 2005), institutionalisation (Wolfensberger, 1969) and eugenic practice (Overboe, 2007). McCarthy’s (1998) findings were similar to those concerning women with physical impairments (Morris, 1989) and non-disabled women (Ahern, Bennett, Kelly, & Hetherington, 2011). All women found it difficult to say anything positive about their bodies. However, dangers of not questioning what is considered 'normal' and 'ideal' are greater for disabled women due to unequal social positioning (Calderbank, 2000; McCarthy, 1998). Unlike Hanna and Lelo, all but one of the women in McCarthy’s (1998) study were living in either institutional or supported community settings with professional assistance. The women had little control over their own bodies: from deciding when to wash and what clothes to wear, to what contraception they used. McCarthy (1998) poses that many of the issues the women had with their own bodies were a result of staff control and a lack of autonomy: attempts were made, through institutional processes, to make them passive pawns in their own lives (Hughes, 2001).

“One woman said it was her keyworker’s decision that she should diet, not her own. Another described the staff’s efforts to control her eating in the following way: ‘They won’t let me have ice-cream, they say “you can’t have this, you can’t have that”. They boss me around’. The

irony was that this woman had, in fact, put on a lot of weight as a direct result of the medication which staff had prescribed and administered.”

(McCarthy, 1998, 561)

Research question one asks what dangers young disabled people face if normative discourse remains unquestioned. Although I maintain normative discourses of sexuality and Youth for Sale are harmful to all young people (especially women), for disabled young people the dangers are greater. Those embodied in ways considered outside the norm, such as Hanna, feel simultaneously excluded from, yet still pressured to meet up to bodily conventions. Yet, we have continually seen that “disabled people are not simply passive victims [...] - many exercise agency and resist” (Reeve, 2002, 493). In *Chapter Six* disabled young people created spaces of resistance within the segregated setting of Explore; in *Chapter Seven* I found disabled youth resisting a discourse of dependency. It is to young disabled participants’ resistance of normative positionings of disability as it relates to sexuality, gender and the body that I now turn.

Disabled youth queering disability

Marie’s fight against sterilisation is written under the title ‘*Challenging the monologue about silent sterilization*’ (Roets, et al., 2006). Marie’s story challenges monologues which reify dangerous and confusing rhetoric that surrounds disability and sexuality. Hughes and Patterson write:

“Meaning follows the name (or diagnostic label), and its iteration and re-iteration produce a particular genus or body with its appropriate signs, symptoms, behaviour and normative expectations.”

(Hughes & Paterson, 1997)

There were many instances of young people I spent time with consciously resisting to live by the “appropriate signs” and “normative expectations” placed upon them in relation to disability, gender, sexuality and the body. The following occurred during the postcards activity with YF (outlined in *Figure 6, Chapter Five*):

“Sue was sitting next to her boyfriend Chris. When it was her turn to share something that annoyed her she joked: “annoying boyfriends!” I wrote ‘annoying boyfriends’ on a postcard, resulting in lively conversation. We later went back through the postcards to think about how things could be different in our future world. I came to ‘annoying boyfriends’, and turned to

Sue, “are we going to leave Chris behind then?” “Nah”, she responded, smiling and patting his leg. At the same time a voice came from the other side of the room: “maybe we should leave behind ‘annoying boyfriends’ and take ‘loving concerned partners’ instead”, Mathew (a young man with the label of ‘intellectual impairment’), suggested. The group agreed, and that was that, ‘annoying boyfriends’ stayed in the past, whilst ‘loving concerned partners’ came with us to the future.”

(Research diary, 23rd November 2011, after first future workshop, YF)

Like in Marie’s story, the young disabled people I spent time with challenged both discourses of asexuality and hypersexuality surrounding disability (Liddiard, 2012), supporting me in answering research questions four: what can youth and the lived-experiences of young disabled people teach us about disability? Stories like the above move disabled young people away from the realms of Youth as Passive; challenging disability’s relation to passivity. We see not only a disabled couple (Sue and Chris) engaged in a long-term relationship, but also Mathew, a young man with the label of intellectual impairment, proposing that the gender neutral conception of “loving concerned partners” be a requirement of our ideal world. This is far from the heterosexual expectation of normative adulthood that is placed upon non-disabled young people (Gordon & Lahelma, 2002), and simultaneously denied to disabled young people (Morris, 2002).

YF also stipulated that there should be “more disabled role models on TV”. CDS literature notes the lack of disabled role models for disabled youth (Butler, 1998; Priestley, 2003); a feeling echoed by the young people I spent time with. Reeve (2002) argues that the lack of disabled role models means demonising and/or paternalising discourses of disability go unchallenged. Like Garland-Thomson (2002), Reeve uses the case of disabled fashion models as an example of disabled people challenging normative discourses of beauty through the popular media. Writing in relation to a 1998 edition of style magazine *Dazed and Confused*, Reeve argues that disabled fashion models challenge an ideal female figure that has traditionally excluded disabled women. Garland-Thomson’s (2002) arguments resonate with those of Reeve, and she terms such a resistance “inadvertent activism”:

“... the emergence of disabled fashion models is inadvertent activism without any legitimate agent for positive social change. Their appearance is simply a result of market forces. This both troubling and empowering form of entry into democratic capitalism produces a kind of instrumental form of equality: the freedom to be appropriated by consumer culture. In a democracy, to reject this paradoxical liberty is one thing; not to be granted it is another.”

(Garland-Thomson, 2002, 24)

Embla and Freyja agreed with Reeve (2002) and Garland-Thomson (2002) that integrating disability into consumerist fashion industries could be a force for change. We saw this in Freyja’s story of the high-heeled shoes in *Chapter Seven*. Furthermore, as outlined in *Chapter Five* Embla and Freyja were running a youth group, *Breaking through Limitations* for disabled teenage girls. The group used methods of informal education to introduce the young women to the histories of political movements including disability rights, independent living and feminism; encourage confidence building and self-expression; and act as a safe space for the girls to ‘be disabled teenage girls’ and spend time with other young disabled women. During the sessions Embla and Freyja utilised a particular image of disabled fashion model, Aimee Mullins:



Figure 26 *Aimee Mullins image used in Breaking through Limitations*

Mullins was one of the models in the *Dazed and Confused* article Reeve (2002) cites. Garland-Thomson (2002, 25) also engages with Mullins’ career, hailing her as “an icon of disability pride and equality”. Thirteen years after the magazine feature British tabloid newspaper, *The Daily Mail*, ran a feature on Mullins when she was made global ambassador to make-up company, *L’Oréal Paris* (along with Jennifer Lopez, Beyoncé,

Eva Longoria and Cheryl Cole) (O'Brien, 2011). Rather than embrace Mullins' differences, however, the journalist takes a different tact, declaring that, "peachy-skinned, hazel-eyed and blonde, Aimee possesses the natural requisites for promoting beauty products" (O'Brien, 2011). The particular image Freyja and Embla used shows Mullins lying on a bed, modelling a short white lace dress with a single strap. O'Brien's claims are understandable; in many ways Mullins embodies the image of ideal women I critiqued in *Chapter Three*. What makes this image different, however, is contrasting the white, 'angelic' imagery which makes up the rest of the photograph, are Mullins' two black prosthetic legs, which Mullins is fiercely focusing upon. Garland-Thomson writes:

"Mullin's prosthetic legs [...] parody, indeed, proudly mock, the fantasy of the perfect body that is the mark of fashion, even while the rest of her body conforms precisely to fashion's impossible standards."

(Garland-Thomson, 2002, 27)

Whilst Mullins mimics idealised womanhood, her prosthetic legs mock that which, in other ways, she conforms to. Embla and Freyja similarly felt it necessary, as disabled young women, to gain recognition within consumerist "normative, public sphere[s]" (Garland-Thomson, 2002, 25), before they could consciously reject its appropriation. This became apparent going downtown on my first Friday night in Reykjavik:

"Embla's arrives to pick me up so I rush out. Freyja's going to meet us later, Embla tells me: she still needs to do her makeup. She takes *ages* doing her make-up, so will probably be late. I turn to look at Embla: she's wearing a black dress, leather jacket, heeled boots, face made-up, and hair done. Nothing unusual there, she always looks great. I catch a glimpse of myself in the rear-view mirror: make-up-less, hair a mess. I look down at my attire: the usual jeans, my most 'Icelandic' woolly jumper, hidden under my raincoat. Gloves, hat and snow-boots finish the outfit off nicely. Mum would be pleased at least: very sensible clothing for the cold weather. Maybe I won't feel so comfortable with the hipsters of trendy downtown Reykjavik though. "You look nice", I say to Embla, "I'm going to feel a right scruff coming out with you two". "Don't worry about it", Embla reassures me, "it's okay for you, you're not disabled. I have to get dressed up; don't want to live the disability stereotype!"

(Research diary, 4th February 2012)

What Embla meant in the above vignette was that for me, as a non-disabled woman, to not get dressed up could be a feminist decision: to challenge the stereotype of 'feminine beauty' women are pressured to conform to. For Embla the situation is arguably more complicated: she describes this as her 'feminist/disability problem'. Despite a feminist

impulse to challenge the objectification of women, Embla feels it more important to assert herself as a gendered and sexual being. She enjoys getting ‘dressed up’ but does not feel she can ever take the ‘not bothering’ option without (as Embla puts it) ‘living the stereotype of the cute little disabled girl’; the asexual disabled person (Garland-Thomson, 2002). If we think back to Ashley X, “presented as someone who will always be a sweet, easy-to-manage little girl” (Hall, 2011, 4), we appreciate Embla’s rejection of the normative expectation on disabled young people to remain eternal children as a political act of disability consciousness. Heading downtown in Reykjavik on a Friday night Embla and I challenge our own axes of normative expectation. By not conforming to the dress code of most young women out that night, I rejected the appropriation of consumer culture which objectifies women. Yet, by conforming to the same dress code, as a young disabled woman, Embla makes her own statement that disabled people are gendered and sexual beings too. As somebody ‘differently embodied’, Embla mocks Youth for Sale, in a way my normatively embodied ‘dressing up’ would not.

We see the paradoxical character of this scenario, and what Garland-Thomson (2002) means when she tells us that the appropriation of disabled women is both liberatory and oppressive. On the one hand, the appropriation of disabled women brings disability into normative consumer culture, “enabl[ing] people with disabilities [...] to imagine themselves as a part of the ordinary, albeit consumerist, world rather than as a special class of excluded untouchables and unviewables” (Garland-Thomson, 2002, 25). Yet, figureheads such as Mullins simultaneously promote a continuing objectifying gaze upon the female body. Although in her modelling photographs Mullins’ prosthetic legs differentiate her from other fashion models, like O’Brien (2011) highlights, she is not so different from any typical fashion model. Mullins is young, slim, and conventionally attractive. I wonder whether images of Mullins can free young women such as Hanna in the story above from feeling “too fat and ugly” to be what women ‘should be’. Furthermore, although Garland-Thomson (2002, 25) cites Mullins as “an icon of disability pride and equality”, a snippet from the article in *The Daily Mail* tells a different story:

“Ever since [her first modelling job], her [Mullins’] ambition has been to shed the disabled tag. ‘And now it has happened,’ she [Mullins] says. ‘With L’Oréal, I get to be Aimee Mullins, model. No qualifier. And that means everything to me.’”

(O’Brien, 2011)

I do not know whether these are Mullins' feelings or the result of tabloid spin. However, I speculate that O'Brien's (2011) *Daily Mail* piece reached a larger audience than the Garland-Thomson (2002) article. Although Garland-Thomson (2002) coherently argues Mullins into a narrative of disability pride, O'Brien instead entwines the normalisation of disability, with a story of a 'supercrip', 'achieving despite of' disability. We are told that Mullins' career not only takes in modelling, but work at the *Pentagon* and competing as an Olympic athlete. I do not wish to deny disabled young women disabled role models akin to the images of non-disabled women. Although I remain hesitant, after spending time with disabled young people, taking into account the words of Reeve (2002) and Garland-Thomson (2002), I err towards feeling that whilst the bodies of few non-disabled women continue to be held in high esteem by consumer culture, we need to see images of disabled women alongside them, troubling conceptions of asexuality that surround disability.

However, just as I feel icons such as Jennifer Lopez do little to enhance the lives of disabled and non-disabled girls, neither do I think role models such as Mullins allow disabled young women space to become in a multiplicity of ways. From my story of going downtown with Embla, it seems Embla feels, as a disabled young woman, added pressure to live up to Youth for Sale in order to prove people wrong and not 'live the disability stereotype'. Figureheads such as Mullins may increase pressure on disabled girls to fit into a normalising discourse of Youth for Sale. I strongly believe, however, that dis/abled girls and young women *should* have access to a variety of dis/abled role models, and that there are much more positive disabled role models that can be established. Indeed, I saw Embla and Freyja acting as role models to girls in *Breaking through Limitations*. I argued in *Chapter Seven* that young people at YF were engaged in "academic activism" (Garland-Thomson, 2002, 24); together sharing experiences, talking through and challenging disability oppression, in ways which helped them to resist internalising psycho-emotional disablism (Reeve, 2002). As well as "inadvertent activism", Embla and Freyja were also engaged in "academic activism" (Garland-Thomson, 2002, 24). They used the image of Mullins as a stimulant for discussion alongside a number of other texts which equally, albeit differently, challenged conceptions of disability in regards to gender and sexuality. *Figure 27* below shows two pictures Freyja used alongside the image of Mullins in a session focusing on stereotypes.



Figure 27 Stacey Herald and Alison Lapper pictures used in Breaking through Limitations, Iceland, 7th March 2012

The images featured on one *PowerPoint* slide. The top photograph shows Stacey Herald, a disabled woman with ‘short’ limbs, and her toddler-aged daughter. The woman and toddler are dressed in similar colours, both sitting, and the mother is only slightly taller than the child. The mother is holding up her t-shirt to reveal her heavily pregnant belly, which the toddler has laid both hands on and both are obviously enjoying. Freyja informed the group that doctors had advised Herald not to have children; nevertheless, this would be her third baby. The picture below Herald shows Alison Lapper, disabled

activist and artist. She is photographed naked, in black and white, along with her son, who whilst standing is only slightly shorter than Lapper, who is sitting. There is much that could be said about this image. The only colour in the photograph is a pair of arms, highlighted in pink, which are supporting the child's upright position. They lay as a challenge to the engrained falsity that a mother should be the sole carer of a child. The picture shows a body without organs. Shildrick (2009) notes that challenging the autonomous self causes particular anxiety in regards to sexuality. The closeness of mother and child portrayed in this image, despite an anonymous third pair of arms, tell us that interdependency does not forego any bond between mother and child. Lapper is leaning towards her son protectively, and like Reeve (2002) theorises in relation to the *Dazed and Confused* fashion shoot, she is staring and turning the gaze back at the audience. Freyja used the images to debunk stereotypes, discussed earlier in this chapter, and in *Chapter Six*, of disabled women as unfit mothers (Tilley, et al., 2012). The conversation aroused when Freyja informed the girls that Lapper had created and displayed a statue of her naked, pregnant self in Trafalgar Square (*Figure 28*) shows how successfully the message was delivered:



Figure 28 Alison Lapper Statue displayed in Trafalgar Square

“Freyja asked the girls why they thought there was so much controversy around the Alison Lapper statue. Straight away Julia responded: “because people don’t want to see a pregnant disabled woman”. Later, after talking about media stereotypes, Freyja asked how attitudes towards disabled people could be changed, Julia said through education. “Who should do the educating?” asked Freyja. Julia was sure of this answer: “disabled people, of course””

(Research diary, 7th March 2012, after *Breaking through Limitations*)

Like YF members cited in *Chapter Seven*, Julia feels disabled people need to educate others about lived-realities of disability. We have seen over the last three chapters all my

young participants were already doing this, whether it be through overt, inadvertent or academic disability activism.

Discussion

Commodified discourses of Youth for Sale abstract youth from the lived-realities of young people's lives, to make 'youth' an idealised signifier of the feminine body (*Chapter Three*). In this chapter I have addressed research question one by asking what dangers young disabled people face if we fail to question normative notions gender, sexuality and the body. I have highlighted that young disabled women's exclusion from idealised discourses of youth, do not mean they escape pressures to meet up to female bodily conventions. We have seen the danger of young disabled women internalising the oppression of psycho-emotional disablism resulting from this exclusion (Reeve, 2002). Furthermore, I have highlighted how a discourse of asexuality works with normative developmental discourse to root disabled people as eternal children (Kim, 2011), justifying enforced contraception and sterilisation (McCarthy, 1993).

Research question four asks what youth and the lived-experiences of young disabled people teach us about disability. We have seen in this chapter young disabled women challenging discourses of asexuality that surround disability. Firstly through 'inadvertent activism' (Garland-Thomson, 2002) they mimic normative womanhood; refusing to live the (as Embla put it), 'asexual stereotype of the cute little disable girl'. Through their mimicry, however, they also help me to answer research question three: what can disability and the lived-experiences of young disabled people teach us about youth? By refusing to let their non-normative embodiments position them outside womanhood, they mock normative womanhood. They crip conceptions of ideal bodies equated with Youth for Sale. Furthermore, by using their 'academic activism' alongside their 'inadvertent activism' (Garland Thomson, 2002), we saw Embla and Freyja explicitly challenging disability's positioning as Other. They argue that disabled people are gendered and sexual beings and the feelings of disabled young people around sexuality are similarly complex to other young people (Slater, et al., 2012). Furthermore they rightly insist that disabled women can be equally good mothers as their non-disabled counterparts.

I turn now to the final discussion chapter, where I bring together arguments made over *Sections One* and *Two* to think about what we have learnt about youth, disability and becoming-in-the-world-together (Shildrick, 2009).

Discussion

Learning with and about youth, disability and becoming-in-the-world-together

Introduction

Mr Reasonable has been in my mind, to differing degrees, throughout the time I have pondered over youth and disability. I have heard many stories of ‘reasonableness’. Some of these reasonable stories I have shared through my thesis to highlight dominant and dangerous conceptions of youth and disability. I explained in my opening letter that I wanted to use my grounding in CDS to cast a critical eye over ‘official textbooks’ (Titchkosky, 2000) of youth and disability. I outlined that I would do this through a constant ‘queer(y)ing’ (Gibson-Graham, 1999) of youth and disability. Taking an intersectional approach, I argued, would allow me to question other phenomena encountered along the way. I have not only asked what youth and disability teach us about one-another, but how they help address wider questions about different and prioritised ways of living; how we become-in-the-world-together (Shildrick, 2009). I use this final chapter to reiterate, in relation to my research questions, what I have learnt through situating myself at the intersection of youth and disability, and outline how the findings can be utilised.

I began my thesis by addressing Mr Reasonable, as a person who strived to meet normative ideals. I maintained that, like all of us, Mr Reasonable would fail in this task (McRuer, 2006). Yet, by unquestioningly striving for ableist, adultist normativity, I have shown Mr Reasonable puts those who do not/cannot/refuse to conform in danger. This worry was at the crux of research question one: what dangers do young disabled people face if normative discourse remains unquestioned? In *Chapter One (Figure 1, p.40)* I outlined the pedestalled signifiers of normative adulthood. From that point onwards we have seen the dangers of not questioning normative adulthood for disabled youth. I address the findings relating to research question one under the heading of ‘*The dangers of not questioning normativity for disabled youth*’.

I argued in *Chapter Two* that disabled youth are threatened by political climates of disposability (Giroux, 2009) as a discourse of passivity is used to justify the removal of life-sustaining assistance and support (Hughes, 2001). This illuminated the importance of research question two: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient? I argued in the introductory chapter that research question two is both method/ological and theoretical. After addressing research question one, I explain how employing a transdisciplinary, intersectional, queer(y)ing approach to research and theory has enabled me to share the stories of disabled youth in order to position them as active and politically resilient. Findings relating to research question two come under the heading, '*Research repositioning disabled youth as active and politically resilient*'. I pose here theoretical and methodological suggestions for further research.

Research question two has demanded theoretical experimentation which has allowed me to not only highlight the active resilience of disabled youth, but also explore the potential of considering youth and disability alongside one-another. Therefore, I have addressed research questions three and four: what can disability and the lived-experiences of young disabled people teach us about youth? And what can youth and the lived-experiences of young disabled people teach us about disability? Discourses of youth and disability have challenged, queered and crippled one-another. My intersectional, critical questioning approach has meant we have not only learnt from and about youth and disability, but explored other identities with which youth and disability intersect, compliment and collide. The conceptual lenses of youth and disability, alongside the embodied lived-experiences of disabled youth, have allowed me to challenge what youth and disability have come to stand for. From *Chapter One* onwards we have seen that ableism and adultism can be hard to separate. I therefore address research questions three and four together under the heading, '*Learning from and about youth, disability and the lived-experiences of young disabled people*'.

I conclude by calling for a culture of critical youth. I outline some implications of my findings for policy and practice, before readdressing Mr Reasonable to reflect on what we have learnt.

The Dangers of not questioning normativity for disabled youth

Research question one: what dangers do young disabled people face if normative discourse remains unquestioned?

Mr Reasonable endeavours to embody normativity. For disabled youth, leaving normativity unquestioned is dangerous. I outline the key findings in relation to research question one below.

Psycho-emotional disablism and internalised oppression

Chapters Seven and Eight confirmed arguments from *Section One*, that disabled youth feel excluded from both normative discourses of youth as becoming-adult and idealised discourses of Youth for Sale. This exclusion amounts to psycho-emotional disablism (Reeve, 2002). Feelings of exclusion from normative discourses of youth “[undermine] the emotional well-being of disabled people and can be just as disabling as structural barriers” (Reeve, 2002, 493). In *Chapter Seven* Clare said that patronising attitudes made her feel like an alien. Colin at YF was tired of falsely being portrayed as a scrounger, dependent upon an economically productive, non-disabled, adult population. In *Chapter Eight* we saw the dangers of Youth for Sale to young disabled women. Hanna at Explore told me she was ‘too fat and ugly’ to be what women ‘should’ be. Furthermore, Freyja warned us that the pairing of disability and asexuality meant that growing-up she wondered whether she had the right to a sexual identity.

Eugenic legacies

In *Chapter Eight* I highlighted dangerous relationships between disability, youth and sexuality functioning to posit disabled people’s bodies as a) childlike (Johnson, et al., 2010), b) asexual (Garland-Thomson, 2002; Liddiard, 2012), and c) the property of others, to be subject to intervention (Barton, 1993; McCarthy, 1998). Continued eugenic tendencies mean disabled young women are threatened by coercive sterilisation and long term contraceptive procedures (Roets, et al., 2006). Furthermore, the continued positing of disabled people as subhuman (Overboe, 2007; Wolfensberger, 1969) within welfare-cutting political climates, increases the risk of institutionalisation. Combined, there is a heightened risk of physical abuse (Hassouneh-Phillips & McNeff, 2005).

Disposability and space to be/come

Together, the above dangers confirm my worries from *Chapter Two*. Western conceptions of adulthood prioritise certain ways of being over and at the expense of others; devaluing and threatening the lives of those that do not/cannot/refuse to conform to the ways of 'neoliberal man'. Current welfare-cutting political climates create a climate of disposability threatening, amongst others, disabled youth (Giroux, 2009).

However, I have consistently shown that "disabled [young] people are not simply passive victims of [...] disablism - many exercise agency and resist" (Reeve, 2002, 493).

Resistance has emerged through subtle redefinition of space (McRobbie, 2000) (*Chapter Six*); inadvertent (*Chapter Eight*) and academic activism (Garland-Thomson, 2002) (*Chapters Six to Eight*); as well as through overt identity political fights (*Chapters Six to Eight*). Resistance is easier when young disabled people have spaces to talk-through feelings of shared oppression with other disabled people. We saw in *Chapters Seven and Eight* that YF, *Breaking through Limitations*, and the Icelandic ILM gave those involved the chance to share experiences of disablism with both disabled peers and older disabled people. In concurrence with Reeve (2002) and Murray (2002) having these supportive networks is important to young disabled people's ability to resist internalising dis/ableist oppression.

With the above dangers mind, it is not surprising that, as I showed in *Chapters Seven and Eight* young disabled people felt they needed to assert themselves in normative discourses of youth as becoming-adult/woman. Identity political battles show disabled youth to be "no different from any other person" (Colin at YF). Thus, they move disabled youth away from discourses of disposability. Yet, these battles present me with other concerns. In *Chapter Six* the story of Sooboo and the dentist at Explore illustrated a 'leisure' service for disabled youth attempting to steer disabled youth to normative adulthood (Goodley & Runswick-Cole, 2010; Murray, 2002; Priestley, 2003). In *Chapter Seven* I argued that for my young disabled participants, asserting themselves within normative discourse was not necessarily a desire, but a means of survival. I worried that disabled youth were denied a) the time and space to 'be young people', and b) opportunities to be/come as disabled people in a multiplicity of different ways (Ferguson & Ferguson, 2001). Therefore I maintained the need to not only question discourses of disability, but simultaneously pick-apart dis/ablism as it functions with normative discourses of age. Whilst there are times in which it is strategically important to argue

young disabled people's 'sameness' within normative discourse, at other times, such as through the writing of this thesis, it is important to challenge said normativity (Spivak, 1988). Furthermore, I believe it is imperative for these battles go on simultaneously, as and when it is necessary for a particular political purpose; an argument I expand below.

Research repositioning disabled youth as active and politically resilient

Research question two: how can disability researchers share the stories of young disabled people in order to reposition them as active and politically resilient?

I have continually asserted that my thesis is only of value in terms of its political purpose. According to Goodley (1999) disability researchers should bring to light exclusionary environments, but also show how resilience is borne out of said exclusion. In *Chapter Two* I argued that removing life-sustaining assistance and support is justified by marking disabled people as passive and burdensome (Hughes, 2001). The dangers posed above highlight the importance of demonstrating the activity and resilience of disabled youth; the heart of research question two. For my disabled participants at YF and in Iceland who were overtly involved in disability politics, simply sharing stories of their identity political battles would have demonstrated their active political resilience. I made the decision, however, to use my thesis as a means of asking what various disciplines can teach us as disability researchers, and vice versa. The reasons for this were multiple.

Firstly, only sharing stories of overt political engagement would have done a disservice to Explore members without said engagement. As I outlined in *Chapter Seven*, disability politics and research has been criticised for leaving aside those with labels of intellectual impairment (Goodley, 2001). In *Chapter Six*, therefore, I drew on feminist critiques of youth subcultural research to highlight disabled youth with labels of intellectual impairment creating their own youth cultural spaces. Secondly, as I argued in *Chapter Two*, the barriers young disabled people face in their 'transition to adulthood' are well documented within CDS literature (Morris, 1999). As a PhD student, I have been allowed the time and space to read, reflect and theorise around youth and disability. My job was not only to reiterate what others had already said, but to contribute to the body of knowledge surrounding youth and disability. Crucially, my wonderings had to support and enhance the political work of my young disabled peers.

To this end, although my analysis over *Chapters Six to Eight* did not dispute the barriers young disabled people face in their ‘transitions to adulthood’, I used these barriers to ask wider questions about youth, disability, adulthood, womanhood and sexuality. *Chapter Six*, for example, showed some of the physical barriers young disabled people face to access the same spaces as their peers. Drawing on Titchkosky (2011), this lack of access prompted me to ask what disabled youth could teach us about youth culture. In *Chapter Seven* I highlighted that paternalistic attitudes towards disabled youth remove them from a discourse of youth as becoming-adult. Drawing on Deleuzoguattarian theory, I wondered what this taught us about the ableism inherent to discourses of adulthood. Finally in *Chapter Eight* we saw how discourses of asexuality rooted disabled people as eternal children, highlighting the dangers of normative discourses of womanhood. I outline what these explorations have taught us in relation to research questions three and four below. First, however, I outline some methodological suggestions for further research which aims to side with disabled youth. I also reflect upon my own methodology.

Intersectionality

In the introductory chapter I argued the importance of researchers stressing disabled youth’s intersectional identities (Goodley, 2011). After spending time with young disabled people, I assert this more strongly than ever. In *Chapter Six* we saw young disabled people who did not necessarily have ‘disabled identities’. Yet they did identify as ‘youth’. In *Chapter Eight* I shared the stories of young disabled people fighting to be recognised as gendered and sexual beings. To not take an intersectional approach to research undermines young disabled people’s own efforts to assert themselves as aged, sexed, gendered, raced, and so on.

My research has considered stories of growing up. I have shared my own stories and stories I have read through the research of others, alongside the stories of my young disabled participants. In *Chapter Eight* I used the term ‘axes of normative expectation’ to highlight that ‘normativity’ is relative. Different expectations are put upon different young people, dependent on a host of intersectional identities. Garland-Thompson’s (2002, 24) term ‘paradoxical liberties’ is useful. Although sometimes the different expectations put on young people may seem oppositional, it is too simple to say that one side is ‘liberated’ whilst the other is ‘oppressed’. Feeling constrained by and excluded from certain discourses, such as those of normative femininity and sexuality we saw in

Chapter Eight, is similarly angst-inducing (Slater, et al., 2012); harking to the importance of questioning normative expectation at whatever angle it comes at us.

I acknowledge, however, that my research has focused on gender and sexuality. This is not to say that gender and sexuality influence expectations placed upon young people more than other intersectional identities. Rather, perhaps due to my feminist perspective and the close female friendships I developed during fieldwork, gender and sexuality were the themes that arose with participants. There is space and a need, however, to work with other young disabled people to consider intersections of youth, disability and race, ethnicity, religion, nationality, class, and so on.

Transdisciplinary engagement

Intersectional approaches to research *demand* transdisciplinary engagement. I have utilised transdisciplinary theories and methodologies throughout my thesis. I outline what I learnt from this engagement through discussions of research questions three and four below. Imperative in answering research question two is disseminating the stories of my young disabled participants not only within CDS, but across (and outside) academic disciplines. I highlighted in *Chapter One* that disability is rarely considered in more critical studies of youth. Findings from research question one highlight the importance of disability entering the imaginations of those outside CDS. As a CDS researcher, I have learnt from other disciplines such as youth subcultural studies, the new sociology of childhood and critical psychology. Yet these disciplines can equally learn from CDS and the perspectives of disabled youth (Slater, 2012, f.c.).

Transdisciplinary engagement has opened avenues for further transdisciplinary conversations. I am personally excited to delve further into youth subcultural studies to see what postmodern texts can offer me as a youth disability researcher. The twenty-first century has been deemed by some as the post-subcultural era; conceptions of youth culture thought unsuitable for an “increasingly globally interconnected world where ideas, styles, music, people, technology and capital circulate and collide in complex ways” (Muggleton & Weinzierl, 2003, 7). My engagement in this thesis was with a limited number of fairly old texts. I justify my utilisation as it is on the back of these texts that newer cultural theories have been developed (McRobbie, 1990; Muggleton & Weinzierl, 2003). Nevertheless, CDS researchers should engage with the newer ‘post-

subcultural' texts to ask how, for example, social networking alters young disabled people's cultural experiences.

Queer(y)ing inside/outside academia

Moreover, the repositioning of disabled youth must not remain within academia (and social networking can help us here). Indeed, participant's stories show that challenging dis/ability, youth and adulthood, is already going on through day-to-day interactions of disabled youth. Our job as disability researchers is to support and enhance those challenges to normativity, so they are cast not as devalued difference, but productive possibility. One way we can do this is by queer(y)ing an inside/outside of academia divide. I explained in *Chapter Five* that some of my participants delivered key note addresses at MMU's *Child, Family, Youth and Disability 2012* conference. Here keynote presenters aged between eight and forty-something taught us about child, family, youth and disability. Despite different lengths of life, academic titles and levels of 'education'; despite differing dependencies on *PowerPoint* slides, notes, PAs, interpreters, Mums, Dads, brothers and sisters; despite our different perceived levels of grownupdom, we were all becoming-theorists-and-scholars-together. My thesis is drawn towards and cries out for more 'opening-up' and queer(y)ing of academia itself. I return to this below, when I call for cultures of critical youth.

Learning from and about youth and disability, and the lived-experiences of young disabled people

We have seen from *Chapter One* onwards that ableism and adulthood are wrapped-up and implicated in one-another. Therefore, to be critically young, I argued in *Chapter Five*, means being both critically queer (Butler, 1993b) and severely disabled (McRuer, 2006). I therefore address the findings from research question three and four together below.

Research question three: What can disability and the lived-experiences of young disabled people teach us about youth?

Research question four: what can youth and the lived-experiences of young disabled people teach us about disability?

CDS perspectives have enabled me to think through and with youth, disability and the lived-realities of young disabled people. This has not only illuminated oppressive discourses of disability, but also the ableism inherent to discourses of youth and adulthood. Research question one asked what dangers young disabled people face if normative discourse remains unquestioned. Findings highlight the urgency of questioning normative discourses of disability, youth, adulthood and so on. As argued in *Chapter Four*, thinking about youth and disability alongside one-another has led not just to the depressing conclusions of research question one, but helped us think otherwise about disability, youth and adulthood. Addressing research question two, asking how disability researchers can share the stories of young disabled people in order to reposition them as active and politically resilient, allowed for methodological experimentation that channels us ways forward as youth and disability researchers. Over *Section Two* disabled young people helped me rethink youth and disability. I outline findings from research questions three and four together below.

Disabled Youth as Active

Stories of disabled youth highlight the falsity of tying disability with passivity. At no point in my research were disabled youth passive. I continually found disabled Youth as Active. In *Chapter Six* I argued that of my participants those at Explore were most in danger of being construed as passive. I showed, however, that they a) were active through their creative pursuits; b) actively asserting themselves as ‘youth’, different to the adults around them; and c) actively creating spaces and claiming back time from semi-formal structures of Explore. In *Chapter Seven* I explained how disabled youth at YF and in Iceland actively fought for disability’s place within a discourse of youth as becoming-independent-adult. Finally, in *Chapter Eight* I showed young disabled women actively asserting themselves as gendered and sexual beings. As explained above, for some of my participants asserting themselves with a normative discourse of Youth as Active was a conscious political act. They insisted that disability did not mean dependency and passivity. They wanted to be considered as becoming-adults/women. However, I have argued that fighting through normative reasonable rhetoric, allowed them to lead lives that challenged the very terms they were employing, and thus,

expanded the meaning of Youth as Active. It is to this I now turn, firstly by considering what disabled youth teach us about youth as becoming-independent-adult; and secondly girl as becoming-woman.

Youth as Active as becoming-in-the-world-together

I explained in *Chapter One* that considering youth as becoming-adult presumes young people striving for adulthood independence. I have concurred with other CDS scholars that the pedestalling of independence threatens the often interconnected lives of disabled people (Erevelles, 2000; Shildrick, 2009). Youth as becoming-adult fails to recognise the situation of disabled youth. Furthermore, my own story of ‘playing-grownup’ in *Chapter One* highlighted that neither does a conception of youth as becoming-independent reflect the lives of non-disabled youth, which are too interconnected (Shildrick 2009).

Rethinking the notion of Youth as Active can therefore be beneficial for all young people. When I found, in *Chapter Seven*, disabled youth actively asserting their place within youth as becoming-independent-adult I used the metaphor of bodies without organs (Deleuze and Guattari, 1972) to argue that ‘independence’ stood for much more than doing things alone. Independence was a term employed in order to make reasonable and possible disabled youth’s interconnected lives; giving them a place in a discourse of youth as becoming-adult.

We saw that disabled youth’s relationships and in/dependencies did indeed change as they grew older. In *Chapter Six* this was considered through the dynamic nature of participant’s relationships with their parents. Some participants found their parents frustrating. Those at YF told me in *Chapter Seven*, that they sometimes wished their parents would allow them the same freedoms as their non-disabled siblings. Yet, in counter-distinction to CDS texts that conceptualise disabled youth’s parents as constraining their independence (Veck, 2002) disabled participants did not desire to break away from their parents. Rather, the message from YF was that their parents needed to learn alternative ways of thinking about disability, outside of medical discourse. I argue below that this points to the importance of intergenerational spaces of critical youth. My young disabled participants highlighted to me that youth is not a time of becoming-independent, but a time of expanding networks of interdependency. As they grew older, my participants’ relationships shifted to include friends, colleagues and comrades; PAs, prosthetics and technology.

Reclaiming youth from Youth for Sale

Young disabled people confirmed that to be accepted as becoming-adults, they had to be acknowledged as gendered and sexual beings. *Chapter Eight* concerned disabled girls' recognition as becoming-women. Freyja and Embla utilised consumerist discourses of Youth for Sale to force disability into the realms of 'the beautiful'. Yet, for these young disabled women, issues of recognition were complex. Although Embla worried about reifying stereotypical notions of femininity, her more immediate compulsion was to challenge, to paraphrase Embla, the 'disability stereotype of the little asexual disabled girl' (Hall, 2011). Disabled youth's fight to be considered the normative is again not necessarily a desire but a means of survival. This highlights the importance of reclaiming youth from consumerist discourse.

In *Chapter Three* I argued feminist-disability conversations are useful to explore gendered experiences of disability and youth. To this end, in *Chapter Eight* I showed young disabled women mimicking, and through this mocking Youth for Sale; expanding notions of youthfulness as they are tied to the body beautiful. Taken alone, however, I maintain that these inadvertent acts of disability activism are not enough (Garland-Thomson, 2002). We can learn from Freyja and Embla's academic activism (Garland-Thomson, 2002). Whilst inadvertently challenging disabled people's positioning as genderless and asexual, they discussed the trials and tribulations of normative discourses of disability, gender and sexuality with teenage girls younger than themselves. Until disabled women are recognised as gendered and sexual, young disabled women will continue to feel ousted from normative discourses of youth. Normative discourses of Youth for Sale therefore need to be challenged to remove youth from discourses of the 'body beautiful' (Priestley, 2003). Whilst young disabled women continue to mock Youth for Sale, we need to support their battles by bringing feminist-disability critiques of commodified female bodies into the public realm.

Breaking binaries: interdependent, incomplete, becoming subjects

As far back as *Chapter One* we have seen how inconsistent, arbitrary and ableist binaries fail to define where youth ends and adulthood begins. As my thesis has continued, the farce of attempting to maintain youth/adult binaries has become clear. Youth/adult

divisions exclude disabled people from discourses of both youth and adulthood. Furthermore, in *Chapter Three*, I questioned a body/social binary, as we saw the bodies of dis/abled women (and to a lesser extent men), being used to make social judgements. Whether thinking about the here-and-now of being young, youth as becoming-adult, or girl as becoming-woman, for the lives of young disabled people to be celebrated, I maintain the importance of appreciating that we are all (child, youth, or adult), interdependent, incomplete, becoming subjects.

We have seen the immediate need of disabled youth holding onto youth/adult (*Chapter Six*), dependent/independent (*Chapter Seven*), woman/man (*Chapter Eight*) and disabled/non-disabled (*Chapters Seven and Eight*) binaries. Yet, all three analysis chapters have also shown how binary distinctions can be unhelpful for disabled youth. We saw in *Chapter Six* that connotations of adult-free arenas that come with ‘youth culture’ are sustained by youth/adult binaries (Hughes, et al., 2005). I argued that this can be problematic for disabled youth wishing to partake in activities alongside their peers (Murray, 2002). In *Chapter Seven* self/Other, dependent/independent, body/social binaries concreted Freyja as unproductive, when she was refused work in a nursery assisted by her PAs. Finally, I argued in *Chapter Eight* that body/social and self/Other divisions oust disabled youth from discourses of gender and sexuality. Thus, disabled young women are pressured to conform to stereotyped notions of femininity. Similarly, dependent/independent divisions mean young disabled women are excluded from conversations about possible future motherhood. Although I maintain that there are times and places where it is necessary for disabled youth and their allies to continue identity political battles, strategically holding onto binary distinctions, and fighting for disability’s place within normative discourse. There must be simultaneous, longer-term battles going on which break down this binary thinking and challenge normativity. I call this a culture of critical youth.

Developing a culture of critical youth

To be critically young one must be both critically queer and severely disabled (McRuer, 2006) (see *Chapter Five*). It requires a constant questioning, queering, and crippling of adulthood normativity. Critical youth is not about chronological age, nor the commodification of youth. Rather, critical youth is about breaking down child/youth/adult binaries. Challenging the pedestalling of adult over youth over child, in

order to listen to and take seriously the words of children and young people, alongside those of adults. Only by listening to those excluded from normative discourse we will see the dangers of an unquestioning approach to normativity (Shildrick, 2003). In *Chapter Seven* those from YF said their parents needed to be educated in alternative ways of thinking about disability. This exemplifies the need for hybrid spaces for critical intergenerational conversations, where dis/abled people can together learn about alternative conceptions of disability, youth and adulthood.

Nevertheless, I have stressed that for wider movements of critical youth to occur without casualty, they will involve different battles, dependent upon time and place. Disabled youth over *Chapters Seven and Eight* showed us that there are times where some need to hold onto binary divisions in order to mobilise (Spivak, 1988); it is sometimes necessary to fight for ones place within normative discourse. We have seen the importance of safe spaces for young and disabled people to share experiences of oppression, rest from inadvertent, and carry-out academic activism (Garland-Thomson, 2002). Camaraderie developed through these spaces equips disabled youth to continue navigating dis/ableist worlds. Similarly, for families, friends, practitioners and other allies of disabled youth, there may be times when it is necessary to support young disabled people by asserting their place within normative discourse. On the other hand, when and where it is safe to do so, one can be a critically young ally to disabled youth by questioning the normativity disabled youth may be fighting for their place within. To be critically young therefore has implications for activism, practice and policy.

Implications of research

Through addressing research question two above I have outlined theoretical implications of my research. However, arenas of critical youth cannot be restricted to the academy. In *Chapter Two* we saw just a few of the devastating impacts welfare reforms in the UK are having on disabled youth; to be critically young means practitioners, researchers and activists coming together to support young people and influence policy.

Linking Activism and Practice

Spending time with YF and Explore alerted me to the importance of disabled, feminist and queer activists joining with practitioners working with dis/abled young people. Intersectional approaches in practice are equally as important as they are in research. In

Chapters Five and Six I worried that youth workers from YF did not appreciate the intersecting multiple-identities of young disabled people; allowing young people to think ‘outside’ disability. Although I stress (further below) the importance of spaces such as YF for disabled youth resisting internalising disablist oppression (Reeve, 2002), I feel youth workers involved should be helping disabled youth to celebrate rather than just normalising disability. This means joining with other movements. From my findings I particularly stress that those working with disabled youth need to learn from feminist and queer movements.

To this end, youth workers at YF could learn from Freyja and Embla. We saw in *Chapter Eight* that discussions in *Breaking through Limitations* opened up the possibilities offered by disability; allowing young disabled women to explore not only their disabled, but sexual and gendered identities. The difference here was twofold. Firstly, Freyja and Embla were speaking with disabled teenagers just a few years younger than themselves. I shared in *Chapter Five* the impact initially meeting Freyja, a disabled woman a few years older than herself, had on Embla. We witnessed in *Chapter Eight* the similarly important relationships Embla and Freyja were carving with teenage girls involved in *Breaking through Limitations*. The importance disabled youth having access to role models and peer support should be noted by those working with young people. Furthermore, unlike those working in YF, Freyja and Embla shared interdisciplinary and intersectional lessons from feminist and queer movements with dis/abled youth. We saw in *Chapter Eight* the importance of this for young disabled women.

Disabled youth and the arts

Whereas those at YF would consider themselves both youth workers and disability activists, those at Explore would identify as practitioners and artists. Explore at times seemed more open to young people’s gendered, raced and aged identities, different religious beliefs and cultural experiences than YF. I have no doubt that Explore offered young people enjoyable, engaging and creative opportunities. However, we saw in *Chapter Six* that Explore staff (at times) slipped into medicalised and pathologised notions of disability. Supporting concerns that organisations working with disabled youth attempt to carve young people into ‘suitable adult citizens’ (Goodley & Runswick-Cole, 2010; Kelly, 2003, 2006; Murray, 2002; Priestley, 2003). Practitioners in organisations such as Explore therefore need to learn other ways to think about disability. Thought

alongside disability, the arts can become a means of ‘therapeutic’ intervention (Lige, 2000) and it is important for groups involving disabled youth in the arts steer away from therapeutic discourses. Again, artists working with disabled youth can learn from activism by listening to, learning from and joining forces with wider disability arts movements.

Policy

Despite the above concerns, I have seen the importance of Explore and YF to young disabled people involved. The *Welfare Reform Bill 2012* means reductions to short breaks for disabled children and young people (Action for Children, 2012), the slashing of youth services (Ramesh, 2011), and cuts to the arts and other creative industries (Higgins, 2012). Organisations such as Explore and YF are under threat; at the time of writing the futures of both look uncertain. Policy makers must take note of the potentially devastating impacts of removing such organisations for disabled youth and their families (Murray, 2002). Rather than removing spaces for disabled youth to spend time, policy should be valuing, funding and finding ways of giving disabled youth access to spaces in which to be critically young (in the ways I have outlined above). As those at YF told us in *Chapter Six*, this means ensuring disabled youth have non-tokenistic access to the same endeavours as their non-disabled peers, as well as spaces to spend time with other disabled young people.

As outlined in *Chapter Two*, my thesis is written at time where government rhetoric stipulates consultation with young people. I have argued, however, that consultation means listening to only the most ‘adult-like’ young people (Fullagar & Owler, 1998). Through my thesis I have shown the possibilities of listening to those at the peripheries (Sargisson, 2000; Shildrick, 2003). We saw in *Chapter Seven* the impact of scapegoating discourses on disabled youth (Garthwaite, 2011). To truly listen to disabled youth, policy makers need to rethink the way they conceptualise disabled youth (Goodley & Runswick-Cole, 2012b). My thesis has shown the strength of the arts for voicing the views of those too often silenced. Although we must ensure the arts do not become colonised as a form of consultation, policy makers could learn from researchers employing inclusive and creative methodologies (for example, Wickenden, 2010), as well as skilful practitioners working within arts-based organisations.

If policy makers listened to and acted upon the concerns and ideas of disabled youth they, like we saw in *Chapter Seven*, would find disabled youth striving to be ‘productive’ members of society. They would also see that the *Welfare Reform Act 2012* denies young people opportunities to be ‘productive’ through their interconnected lives; the shift from *Disability Living Allowance* to *Personal Independence Payments*, for example, removing disabled people’s support to work (Barnett-Cormack et al., 2012; Butler 2012a). If government and policy makers truly want disabled youth to be contributing to economies, policy needs to support disabled youth to live interconnected lives. Yet there also needs to be an appreciation, and indeed a *promotion*, that one can be ‘productive’ and ‘active’ outside the market economy.

Everyday interaction

We see from the above that being critically young involves conversation (in the widest sense of the term – Erevelles, 2005). It means influencing service-provision; writing publicly through both research channels and the social media; but also about noticing our everyday mundane interactions. For those of us already able to assert ourselves within normative discourse, and/or are speaking from a prioritised position which allows us safely to do so, the task is to take up a critically young positionality in all aspects of our lives. We have witnessed through my thesis disabled youth challenging discourses of disability through their day-to-day living. Everybody can learn from this. When we feel ourselves ‘slotting into’ what may be oppressive or exclusionary to our comrades, we need to resist it, and shout about our difference from whatever idealised form it may take. Our task is to unhook youth from adulthood expectation, and relieve dis/abled young and not-so-young people of the pressures of trying to be the mythical adulthood norm. Only then will we be part of a critically young culture within which we can find and celebrate the multiplicity of ways we can become-in-the-world-together (Shildrick, 2009). For a culture of critical youth to thrive, we have to wave goodbye to Mr Reasonable.

Goodbye Mr Reasonable

Dear Mr Reasonable,

It is time reflect upon our journey together, before we part ways. I hope that you, like I, have learnt from disabled youth. Research question one asked what dangers young

disabled people face if normative discourse remains unquestioned. Now you know the dangers your normative ways of being pose to disabled youth, I want you to stop attempting to embody ableist, adulthood normativity, and strive towards inhabiting queer, crip spaces of critical youth. I offer you some final tips here, by sharing with you how I will take up my own gauntlet of critical youth.

I admit Mr Reasonable that being critically young can seem scary. I moved to Manchester aged 22, and moved away aged 24. Have I become-adult during this time? I have certainly experienced new things; things that were previously scary - going to and speaking at conferences, chairing sessions, teaching – I now feel comfortable(ish) doing. I returned from Iceland to my first fulltime job interview and now live back on the right side of the Pennines, lecturing at *Sheffield Hallam University*. Getting this job, I found myself redepoying the phrase I began my PhD with: “shit, this is proper grownup stuff”. Despite everything I have written, it continues to be a phrase that when I feel unsure, not grownup enough to be doing what I am doing, I am tempted to utilise *because* of its implicit meanings. Titchkosky (2007) asks us to watch our watchings and read our readings. Watching how I concrete notions of ‘adulthood’ through speaking and acting within normative discourse is now something I am vigilant to. I hope you will be too.

Through my thesis I have thought through and with youth (child and adult), dis/ability, gender, sexuality, and other intersectional identities, whilst ‘living’ my life, chatting to friends, family, colleagues and comrades. From this I now know none of the things listed above make me any more (or less) ‘grownup’ than when I started my PhD. The scariest thing I have done since writing ‘*Playing Grownup*’ was to fly and live abroad in Iceland. For the first time I was more than an hour away from my parents, brothers and friends. This seemed very ‘grown-up’. Yet I certainly wasn’t alone. As you have heard, I was welcomed into the social circles of the young disabled people at the ILC. I became much more dependent on the disabled young people whose in/dependencies I was theorising around than they were upon me. To make this clear, is to appreciate the dynamic nature of interdependencies. Like the disabled young people whose stories I have shared over *Section Two*, my own dependencies have shifted and changed over the last two years but they are, and continue to be, as present as ever. To be critically young, I endeavour to make my own dependencies, my failure to embody adulthood, overt.

The undergraduate students I now teach are studying *Education and Disability Studies* and many will become future educators. I see this as a valuable avenue of dissemination for my thesis. To act within my convictions, this mode of dissemination is not just theoretical, but pedagogical. To make our classroom a space of critical youth culture we share gendered stories, raced stories, stories concerning sexuality. We talk about how numerous intersectional identities impact on the way we treat children, young people, and *all* people inside and outside the classroom. We think about how the valued signifiers of adulthood affect the way we teach children and young people in schools, and what it may mean for those not meeting the adulthood-ideal, such as disabled people. I try act within my convictions by revealing my own not-being-sure in order to create an atmosphere where we can all not-be-sure, question and think things through together. To be critically young is to break down teacher/student dualities; my knowledge is different to, not greater than that of my students.

Furthermore, being critically young means not being sure extending to my academic pursuits. You have seen this in my thesis. Perhaps, Mr Reasonable, your scientific-self has been challenged by the methodological experimentation I have offered. Firstly in the way I have constructed my thesis, and secondly through my transdisciplinary exploration. The latter has meant that I am in no way 'expert' in the subjects I have delved into. I maintain, however, that to feel completely grounded within the theories I have utilised would not have allowed for the avenues that have been opened up. To begin engagement with disciplines outside CDS, we need to embrace a playfulness to research, which accepts that although our knowledge may not be extensive, it is a starting point for further engagement. It is only by talking through and between disciplines that we can address the politically vital task of considering youth, adulthood, and disability less oppressively.

Like I hope you will, Mr Reasonable, I also try to live-by the teachings of my thesis outside my academic and teaching pursuits. I have learnt from my young disabled participants, and I employ my own methods inadvertent activism (Garland-Thomson, 2002). As outlined in *Chapter Five*, I continue to discuss and learn how I can be a comrade to my disabled peers with some of those I came to know through my fieldwork. I now know that my own inadvertent battles sometimes need to be different to those of my disabled peers. Whereas my young disabled peers mock adulthood through mimicry, for me, mimicry dangerously slips into camouflage, at the expense of those who cannot

conform (Bhabha, 1984). For disabled youth excluded from normative discourse, we have seen the immediate fight sometimes must be for inclusion. Yet, as someone accepted into discourses of independence and femininity, and expected to conform to heterosexual expectation, my battles are different. To offer solidarity to my disabled comrades I highlight my many dependencies, whilst questioning the privileged position independence holds; challenge the commodification of women as sexual objects; and queer heterosexual expectation. Although the different axes of normative expectation young people face mean daily battles are different, they can and must continue simultaneously. The aim is ultimately the same: to challenge normative expectation placed upon young people, in the hope of one day celebrating a multiplicity of ways of becoming.

I, like you, need to avoid being the ‘good native’. I ask you to join me in a quest of critical youth by expanding conceptions of activity; removing the full-stop at the end of youth; flourishing in becoming networks of interdependency; and dwelling in the cracks (Chandler, 2010) of youth and disability. Tell your comrades to be critically young strategically. If it is not safe to be ‘different’ be the same; but when ‘sameness’ seems easy, shout about your differences. For you, Mr Reasonable, my conclusion is simple. Learn from disabled youth, and please, stop playing grownup.

Love,

Jen x

Appendices

Appendix One: 'Report from the Future' booklet used with Explore

(See Chapter Five, Research contexts: Recruitment and methods, for additional context)

<p>TIME TRAVELLER</p> <p>REPORT FROM THE FUTURE</p> <div data-bbox="517 495 826 835" style="border: 1px solid orange; height: 150px; width: 100%;"></div> <p>Time traveller name:</p> <p>Time traveller age:</p>	<p>WELCOME TIME TRAVELLER</p> <p>YOUR MISSION</p> <p>You have travelled forward in time to a world that is just as you like it</p> <p>Here, everything is just as you wish</p> <p>It is your best-ever future world</p> <p>Please use this book to report back on what you find</p>
<p>TIME TRAVELLING TIPS</p> <ul style="list-style-type: none">○ Don't worry if you don't have time to do everything – time travelling is hard work!○ You can draw, stick, colour or write your report – it is up to you!○ Most importantly: this is YOUR best –ever future world, it can be just how YOU want it to be!	<p>YOU HAVE LANDED IN YOUR FUTURE WORLD: WHAT DO YOU SEE?</p> <div data-bbox="954 1305 1390 1843" style="border: 1px solid orange; height: 240px; width: 100%;"></div>

YOU MEET SOMEBODY FROM
YOUR FUTURE WORLD: WHAT DO
THEY LOOK LIKE?



**YOU ASK THEM SOME QUESTIONS,
PLEASE RECORD THEIR ANSWERS
BELOW**

- **How old is the future person?**

- **How does the future person spend their day? Do they have a job? Go to school?**



- **What does the future person do for fun?**


- **Who does the future person live with?**



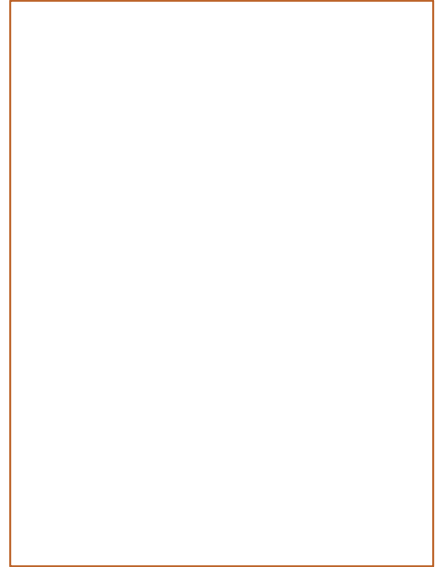
THE FUTURE PERSON SHOWS YOU
WHERE THEY LIVE: WHAT DOES IT
LOOK LIKE?



YOU WANT TO VISIT MORE PLACES.
HOW DO YOU TRAVEL AROUND?



WHERE DO YOU GO? WHO DO YOU
TALK TO? WHAT DO YOU SEE?



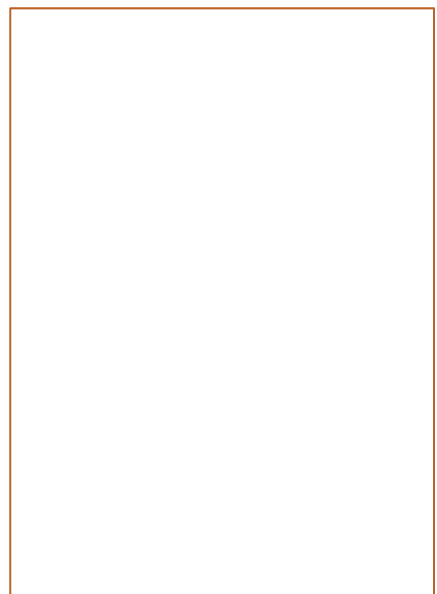
YOU LIKE THE FUTURE SO MUCH
YOU DECIDE TO STAY! TELL ME
ABOUT YOUR LIFE IN THE FUTURE.

Some ideas:

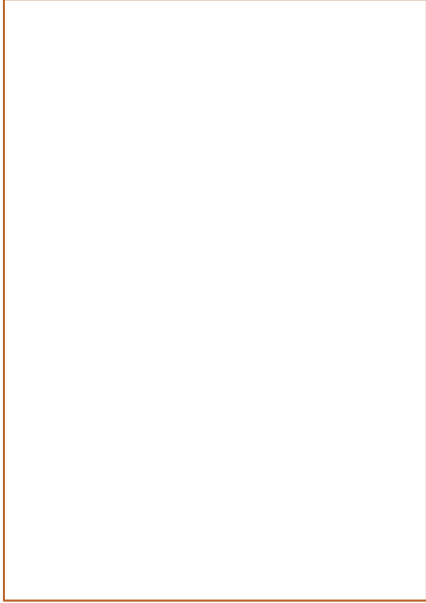
- What do you do?
- How do you spend your time?
- Do you still go to school?
- Do you have a job?
- Who do you live with?
- What is different about your future life to now?



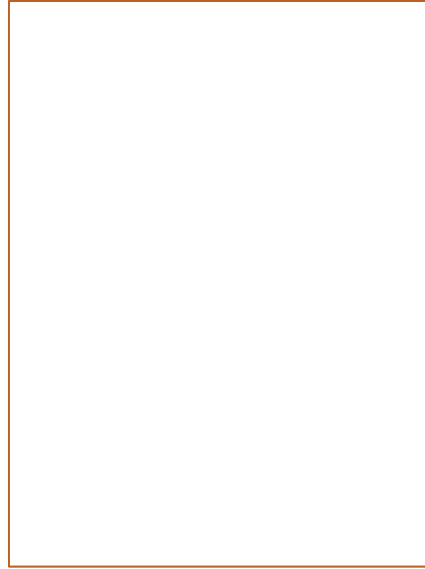
MY LIFE IN THE FUTURE



MY LIFE IN THE FUTURE



ANYTHING ELSE YOU WANT US TO
KNOW ABOUT THE FUTURE?



Appendix Two: 'My day in the future' used with Explore

(See *Chapter Five, Research contexts: Recruitment and methods*, for additional context)

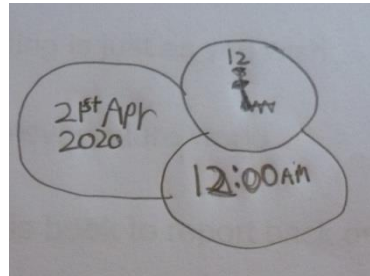
Time	My life now	My life in my best-ever-future world
7am		
9am		

Appendix Three: Example of ‘Instructions from time travelling guru’ used with Explore

(See Chapter Five, *Research contexts: Recruitment and methods*, for additional context)

Instructions for time traveller: Sooboo

You have done brilliant time travelling so far.



You have had some great ideas – I love the character Siusozwayez that you met in the future and the green land with warm winds!

It’s time now to think about making a piece of art that can tell me more about your future travels.

1. Choose something from your report from the future that is interesting for you
2. Think about how you can make this into an art piece

It is good to start by thinking of a dream you have for the future or something that annoys you in your life today, and then building a future world that solves this problem.

Just remember, this is your best-ever future world – anything you find annoying today can be solved in the future!

Thank you time traveller Sooboo.

Appendix Four: Example of final art piece, Explore 1

(Final art piece depicting Santa Pause from Explore's best-ever future world; see *Chapter Five, Research contexts: Recruitment and methods*, for additional context)



Appendix Five: Example of final art piece, Explore 2

(Final art piece depicting Sooboo from Explore's best-ever future world; see *Chapter Five, Research contexts: Recruitment and methods*, for additional context and *Chapter Six* for discussion)



Appendix Six: Participant Information Sheet, Cameras Workshop, Youth Forum

(See *Chapter Five, Research contexts: Recruitment and methods*, for additional context)

Cameras workshop

Take pictures of things that:

a) You don't like



b) Annoy you



c) Stop you doing something

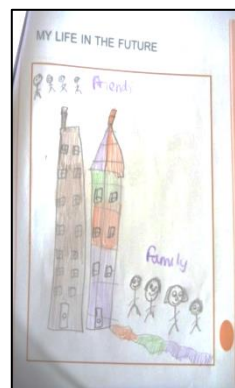


d) You think should be changed



We will use these in a couple of weeks to think about how the world could be different when we design posters about our best-ever-future-worlds.

The best-ever future worlds of young disabled people



As part of my PhD at university, I have been finding out what young disabled people's best-ever future worlds would look like.

In this booklet are some of the things I found out.



With a big thank you to all the young people involved and whose artwork is used here!

For more information contact:

Jenny Slater at jbslater3@gmail.com

Best-Ever Future Worlds Project: summary

Everywhere should be **ACCESSIBLE** to everyone so young disabled people can **CHOOSE** where to go, where they live, the transport they use to get around, and what job they have.



Disabled people should be treated **EQUALLY** to non-disabled people and young disabled people given the same **FREEDOMS** to make their own mistakes.

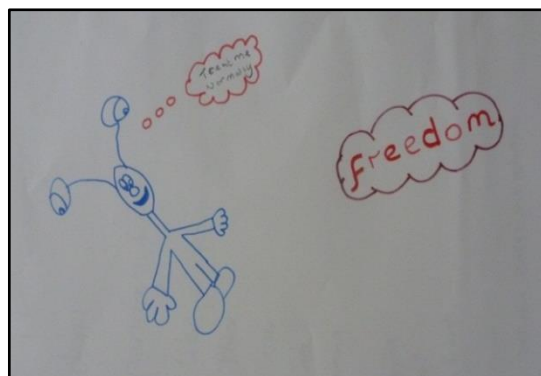


Young disabled people should not be patronised and treated like kids. They can be **INDEPENDENT** adults if given the right support, which they should be in **CONTROL** of. Independence does not always mean doing things on your own.

Adulthood and Independence

In our best-ever future world:

1. Disabled people would not be treated like kids.
2. Young disabled people would have the same freedoms as non-disabled young people.
3. They would be allowed to learn from making their own mistakes.
4. Disabled young people would be treated like adults and given the chance to be independent through having the right to assistance and support.
5. Independence would not mean doing things on your own.



Education

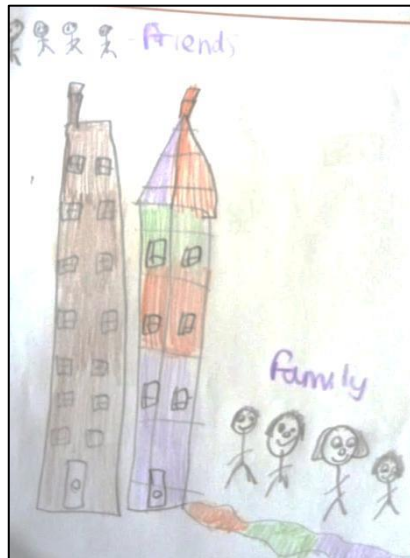
In our best-ever future world:

1. Education would not just happen inside school and college, but outside of it too.
2. There would be lots of trips away.
3. Computers and technology could be used so students could have more control over their education and people could focus on things that interested them.
4. Young disabled people would have the right to assistance and support, which they would be in control of.
5. Teachers would listen to, respect and understand students.
6. Young disabled people would be treated like adults.
7. Everyone would have a chance to speak up and show what they *can* do.
8. Universities would be made accessible to everyone, including disabled people.

Housing

In our best-ever future world:

1. Some people would live with their friends, others with their family, and other people on their own.



2. All housing would be accessible for everybody to live in.
3. There would be good support for disabled people to live independently.
4. Young disabled people would be able to move out from their parents, if this was what they wanted.
5. There would be a range of different places to live, to suit everybody.

Work

In our best-ever future world:

1. Young disabled people would have the right support to find jobs.
2. There would be chances to try different jobs, so you could find one that is interesting to you.
3. Jobs would have good hours, good pay, and a fair boss.
4. Staff would treat each other with respect.

Role models

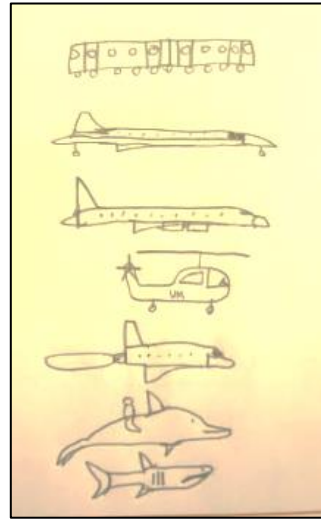
In our best-ever future world:

1. There would be more disabled people on TV, books and radio, so young people would have disabled role models.

Transport

In our best-every future world:

1. ALL transport would be accessible for everybody to use, including people using wheelchairs.



2. Timetables for trains and buses would be easy to understand.
3. Buses would be free for everyone to use.

The Environment in our best-every future world:

1. People would look after and respect the environment and animals.

Free time in our best-every future world:

1. There would be more places for young disabled and non-disabled people to spend their free time which didn't cost money.

Appendix Eight: Introductory posters used with Youth Forum

(See Chapter Five, *Research contexts: Recruitment and methods*, for additional context)

At the forum on the 23rd November we will all become time travellers, exploring our best-ever future worlds.

Wanted
Young Disabled Time Travellers
For a journey to the **Future**

Questions? Email lsbster3@gmail.com
Or speak to Maureen or Colin from the Young Disabled People's Forum

I hope I will see you there!

What if you could travel forward 100 years to a world that is just as you want it?

How do people get around?

Where do people live?

What do people do for fun and entertainment?

What really annoys you?

I just want to get a burger!

Where are the positive images of young disabled people on TV?

That's confusing! Where do I get my train?

Appendix Nine: Participant Information Sheet, Parent, Explore

(See *Chapter Five, Ethics: Procedural Ethics* for additional context)

Dear Parent/Guardian,

My name is Jenny Slater and I am a PhD Researcher at Manchester Metropolitan University.

I am coming to work with the group your child attends at Venture Arts as part of my PhD research.

The young people will be part of a project which uses art to explore the ‘best-ever-future-world’ ideas of young disabled people.

As this is part of my research at university the views of the young people and their artwork may be used in my work, presented at conferences and possibly published in academic journals. If this is the case, the names of the young people will be changed.

I may record interviews with the young people and/or take photographs. Again, your child will remain anonymous in any of my work at university.

I have included a consent form for your child to take part in the project. It would be great if you could return this to the next meeting.

Please do not hesitate to contact me if you require any further information.

Best wishes, and thank you.

.....

Jenny Slater

jbslater3@gmail.com

07804631274

Appendix Ten: Participant Information Sheet, Futures Workshops, Youth Forum

(See *Chapter Five, Ethics: Procedural Ethics* for additional context)

Hello,

My name is Jenny Slater.

I am a student at Manchester Metropolitan University.

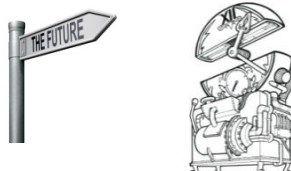
At university I am doing a PhD, which means I have to write a big book called a thesis.

In my thesis I am finding out about the ideas of young disabled people.



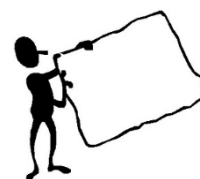
I have come to your youth forum to find out about your ideas of how the world could be different in the future – if you had it just the way you liked it.

On the 23rd November, I will run a workshop where we will pretend to be time travellers, exploring our best-ever future worlds. We might make posters about our best-ever future worlds.



If you agree, I might use some of your ideas and pictures in my work.

I might also present them at conferences.



If I do, I will change your name so people don't know who said what and you won't be able to tell it's you in any photos I use.

There is a form for you to sign if you want to take part in the project, but if you change your mind at any point, that's fine – just let me know.

If you have any questions, just ask, or email me at jbslater3@gmail.com

Thank you for letting me come along to your group!



Appendix Eleven: Consent Form, Young Person, Explore

(See *Chapter Five, Ethics: Procedural Ethics* for additional context)

Jenny Slater

jbslater3@gmail.com

07803631274

Please tick the box if you agree:

Jenny has talked to me about the project	
I understand what the project is about and what I'm going to do	
It is okay for Jenny to use information from the project and photos of my artwork in her work at university	
I don't mind if Jenny records an interview with me when we've finished the project	
I don't mind my picture being taken	
I know I can change my mind about taking part in Jenny's work at anytime	
I know my name won't be used in Jenny's work	
I want to take part in the project	

Name

Signed Date

.....

Appendix Twelve: Consent Form, Parent, Explore

(See *Chapter Five, Ethics: Procedural Ethics* for additional context)

Researcher Contact Details:

Jenny Slater

jbslater3@gmail.com

07804631274

Please tick the box if you agree:

I have been provided with an information sheet about the project	
I understand that if I change my mind at any point Jenny will not use my child's views in her work	
I understand that Jenny may use ideas from and photos of the artwork in her PhD thesis, in published journal articles and at conferences	
It is okay for Jenny to take pictures of my child	
It is okay for Jenny to record an interview with my child at the end of the project	
I understand that my child's name and identifiable photos won't be used in the write up of the project	
I am happy for my child to take part in the project	

Name of young

person.....

Name of

parent/guardian.....

Signed Date

Appendix Thirteen: Consent Form, Young Person, Youth Forum

(See *Chapter Five, Ethics: Procedural Ethics* for additional context)

Researcher Contact Details:

Jenny Slater

jbslater3@gmail.com

07803631274

Please tick the box if you agree:

Jenny has talked to me about the workshops	
I understand what the workshops are about	
I know I can change my mind about doing the workshops at any time	
It is okay for Jenny to use information from the workshop in her work at university	
I know my name won't be used in Jenny's work	
I want to take part in the workshops	

Name

Signed

Date

Appendix Fourteen: Consent Form, Iceland

(See *Chapter Five, Ethics: Procedural Ethics* for additional context)

Researcher Contact Details:

Jenny Slater

jbslater3@gmail.com

07803631274

Please tick the box if you agree:

I am happy for my words and stories to be used in Jenny's thesis	
I understand that my words and stories will be attributed to me	
I am happy for Jenny to use my real name in her thesis... or ...	
... I would prefer for a pseudonym be used	
I understand that these stories may be used in future publications, and am happy for this to happen	
In the case of publication, I am happy for my real name to be used, or...	
.... I would prefer for a pseudonym to be used	
I am happy for Jenny to refer to the organisation, NPA in her thesis	
I have received a draft copy of the thesis chapter which my stories are appearing within	
I would like to receive a copy of the chapter in its final state	
I understand that I can change my mind about being part of Jenny's work at any time	

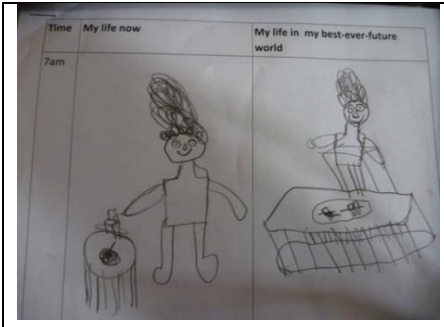

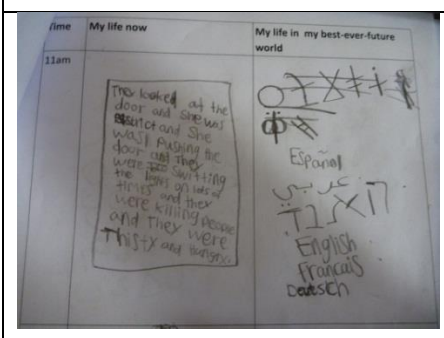
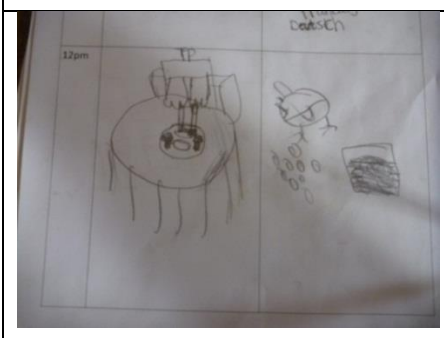
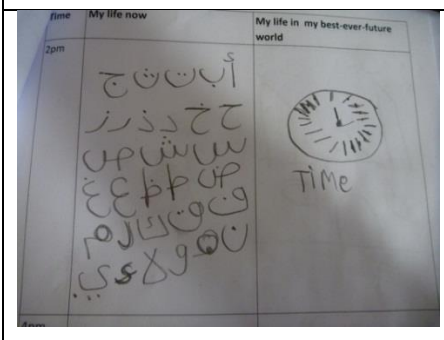
Name

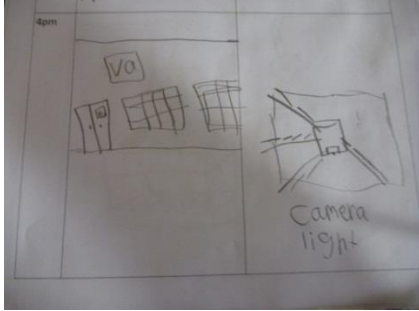

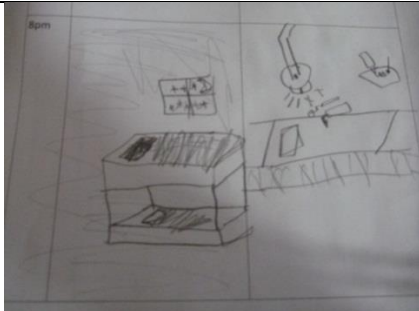
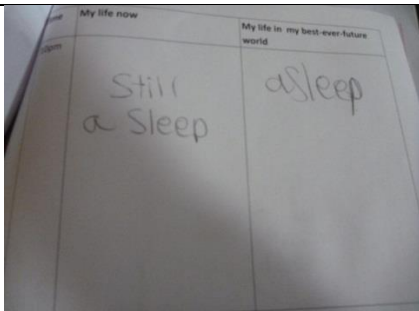
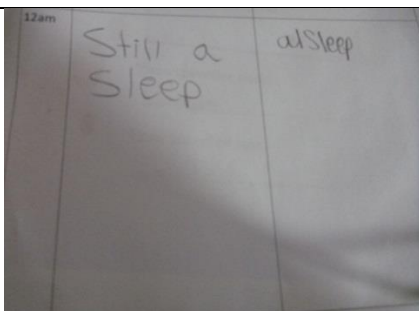
Signed

Date

Appendix Fifteen: Sooboo's 'A Day in the Life'

(Text from an interview with Sooboo about his future day; see *Chapter Six, Youth subcultural studies: Averse to disability?*, for additional context)

<p>Time My life now My life in my best-ever-future world</p> <p>7am</p> 	<p>Usually Sooboo eats his breakfast at 7am. In his future world he would draw the Arabic alphabet.</p>
<p>9am</p> 	<p>Usually at 9am Sooboo is at school. In his future world he would be at 'soft play'.</p>
<p>Time My life now My life in my best-ever-future world</p> <p>11am</p> 	<p>Usually at 11am Sooboo would be writing in school. In his future world he would be learning languages. Spanish would be taught in Spain, by a Spanish woman who didn't know Arabic, Hebrew, English, French or Dutch.</p>
<p>12pm</p> 	<p>Usually at 12pm Sooboo would have lunch. In his future world he would feed the chickens.</p>
<p>Time My life now My life in my best-ever-future world</p> <p>2pm</p> 	<p>Usually at 2pm Sooboo would still be in school. In his future world, he would learn about time.</p>

 <p>4pm</p> <p>Vo</p> <p>Camera light</p>	<p>Usually at 4pm Sooboo would be leaving school. In his future world he would learn about camera light.</p>
 <p>6pm</p> <p>My life now</p> <p>My life in my best-ever-future world</p>	<p>Usually at 6pm Sooboo has dinner. In his future world he would go to mosque.</p>
 <p>8pm</p>	<p>Usually at 8pm Sooboo goes to bed. In his future world he would visit the dentist.</p>
 <p>10pm</p> <p>My life now</p> <p>My life in my best-ever-future world</p> <p>Still a Sleep</p> <p>asleep</p>	<p>At 10pm usually Sooboo is still asleep. In his future world he would also be asleep.</p>
 <p>12am</p> <p>Still a Sleep</p> <p>asleep</p>	<p>At 12am Sooboo is still asleep, but he wakes up whenever he wants.</p>

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