

The Right or Responsibility of Inspection: Social Work, Photography, and People with Intellectual Disabilities

by

Beverley Ann Fudge Schormans

A thesis submitted in conformity with the requirements
for the degree of doctor of philosophy

Factor-Inwentash Faculty of Social Work
University of Toronto

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2011

Abstract

The act of knowing is a critical determinant of what is known, yet there are limits and potential violence inherent in all ways of knowing. Social workers have an ethical responsibility to understand our means of knowing and our knowledge claims – both shape the work we do. Conspicuously under-represented as creators of/commentators on how they are represented, people with intellectual disabilities have had little/no control over what or how they are known. These ethical and epistemological concerns were the focus of this arts-informed qualitative study. The purpose was an interrogative encounter with one way of knowing – how public photographic imagery of people with intellectual disabilities influences knowledge about them. It was concerned, however, to come to this knowledge through an inquiry into how labelled people would, themselves, interpret and respond to these representations, and how they might use photography to trouble disabling images and non-disabled (social work) knowing. Theoretically framed by a critical disability lens, the work was influenced, too, by Derrida's essay on photography, "The Right of Inspection". The other regarding aspect of the philosophy of Emmanuel Levinas, his concern with our ethical responsibility to the alterity of the Other, most powerfully informs the work. Four adults with intellectual disabilities accepted the invitation to participate in this project. First, they critically engaged with a selection of public

photographic images. In a unique methodological turn, they then transformed the images to reflect their critique. Interpretive analysis of the critiques and transformations identified four thematic ideas. Participants' critiques were insightful and profound; transformations provocative and disruptive. Challenging dominant assumptions – and demanding non-disabled others re-think intellectual disability and people so labeled – the critiques and transformations also respond to the social/political/ideological/psychological ramifications of photographic imagery on the lived experience of intellectual disability. Through the work, participants confront non-disabled responses to public photographs and to labeled people, challenging non-disabled others to question their knowledge, attitudes, and behaviours. The work also raises questions about research and people with intellectual disabilities: the possibilities for voice and empowerment through inclusive research strategies and visual methodologies, and the transformative potential of dialogic encounters between people with and without intellectual disabilities.

Acknowledgments

I attempt here to thank all those who have supported me and this work, knowing as I do that whatever I may write will be insufficient to convey both the depth of my gratitude and the breadth of support afforded me over the course of this journey. Beginning, as it did, with the unexpected death of my beloved daughter, Jen, this journey has often been a difficult one. So many people, however, have believed both in me and in the value of the work that I was doing, that this journey has also been, in so very many ways, an incredibly rich and rewarding experience.

Let me begin by thanking the Social Sciences and Humanities Research Council of Canada and the Factor-Inwentash Faculty of Social Work at the University of Toronto for their financial support of this project. Thank you, too, to my colleagues at the School of Social Work at McMaster University for their generously given support and flexibility as I worked to complete this thesis. In particular, I wish to thank the School of Social Work's director, Jane Aronson, whose wholehearted support (combined as it was/is with her wonderful sense of humour) has been indescribably important and helpful. I wish to offer a very special thank you to Chris Sinding. Taking up my academic appointment at McMaster, I was so very, very fortunate to have Chris as a mentor. In addition to helping me to settle into my new position, Chris was also instrumental to the successful completion of this thesis. Her willingness to read (and re-read) drafts has been invaluable. Her warmth, intelligence and sensitivity have influenced my thinking in such wonderful ways and are very evident in the pages of this thesis. Thank you!

It is so difficult to know just how to begin to thank my thesis supervisor, Adrienne Chambon. Her seemingly boundless support and enthusiasm for the project, her commitment and ongoing encouragement, have meant so much. I continue to appreciate her wisdom, guidance, and her own curiosity. Introducing me to new writers, new ideas, new considerations, she has gently pushed my thinking in so many exciting directions and her influence on this final thesis is immeasurable. Thank you, Adrienne.

I would like also to extend my heartfelt thanks to my other thesis committee members, Charmaine Williams and Roger Simon. I extend a special thank you to Roger, for his introduction to the work of Emmanuel Levinas and for his patience, guidance and support of my

efforts to apply these ideas to my own work. Thank you, too, to Kevin Stoddart and Stanley Witkin for their participation in my thesis defense and for their enthusiasm for the work.

Without the support of family and friends, this thesis would never have reached its conclusion and my life would have been far less rich. I wish to acknowledge here a few especially important people. I have learned so much from my classmates (and now friends), Barbara Fallon and Rose Cameron. Commiserating and celebrating every step along the way, together we have shared in each other's journey. I am particularly grateful to Rebecca Renwick, for her knowledge, the innumerable opportunities she offered, and for her unrivalled generosity. I thank Rebecca, for her ongoing and unflagging support, but more importantly, for her friendship. My dear friend, Shawn Macdonald, has been unwavering throughout this journey – never for a moment doubting that I would, indeed, finish and that it would all be worth it. Always there to listen, to talk, to 'hold my hand', her confidence in me was far greater than my own and my words will never be adequate to the task of letting her know the value of her friendship.

It is also not possible to convey to my partner, Jeff, and my lovely little daughter, Frances, just how much they mean to me and how thankful I am for and to both of them. Thank you, Jeff, for everything. And thank you to Frances, whose constant love, endless supply of hugs, and periodic reminders to "smile Mommy", serve to keep my priorities in order, and this work – and life itself – in perspective.

To my dearest Jen: this work, like so much of my life, owes such a debt of gratitude to you, my beautiful girl. You brought such joy into my life and despite your absence you continue to shape and influence me in so many ways every day of my life. I miss you, and I love you.

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Framing the Work

Section 1

Framing the Work

Chapter 1 – The Need to Ask the Question



In order to begin, I must return to an ending, and to a conversation that never took place and is now no longer possible. The work starts with this – a grainy, faded and creased charity advertisement, dated 1985, carefully cut from a regional newspaper and kept in my bookcase. Actually, this is only partially true. Recognizing that I may sound remarkably sentimental, it really starts with a case of love at first sight when, as a very young (and, arguably, even more idealistic) woman, I walked into a community-based group home in time to witness a frazzled adult being thwarted, challenged, and (dare I say) beaten at the game of ‘behaviour modification’, by an opponent standing (sitting, actually) less than 3 feet tall, with beautiful blue eyes and a dazzling (albeit mischievous) smile. This wonderful (and forever strong-willed) little

girl would, in time, become my (foster) daughter, but, in the intervening space between these two events, I was able to be part of her life in my capacity as supervisor of this group home that she had recently been moved to upon the closure of the institution into which she had been placed at the age of 5yrs. While increasingly transforming myself (although initially unaware of such) into Jen's mother, her birth parents retained legal guardianship and thus had decision-making power when asked by the agency operating the group home to include Jen's image in a charity advertisement – the image offered at the introduction of this paragraph.

I ask the reader to keep in mind the year was 1985 - people with intellectual disabilities were, as a rule, still largely segregated in institutions, deliberately and effectively hidden and kept from the public eye. De-institutionalization and community-living were, at the time, relatively new concepts here in Ontario and the notion of public photographic images of labeled people, images created by the (chiefly parent-led) agencies intent upon securing their release from institutions and (re)integrating them into the community, was often greeted with great enthusiasm. I vividly remember my own thrill at seeing a billboard, an *entire* billboard, devoted to an advertisement for community living and including an image of a labeled person. Excitedly driving up and down the road to view it over and over again, my response was anything but a critical assessment of the image itself or its possible interpretations – it was a purely affective celebration of a 'coming out': a coming out of the obscurity wrought by institutionalization, and a more literal coming-out of institutions and coming-in to communities.

Nonetheless, it was this image of Jen and the labeled adults who surround her that ignited a critical awareness and concern for how public images of people with intellectual disabilities were being used. And this undoubtedly derived from my very close and personal relationship with her. I remember most my confusion over the use of the caption "What's wrong with this

picture?” My disquietude was such that when Jen became my (foster) daughter, I requested that her image no longer be used. My partner and I were struggling to integrate her into her new neighbourhood, and concerned not to single her out in a way that might emphasize her disability and mark her as different in an undesirable way.

It is, perhaps, ironic then that when Jen died we chose to use her image in fundraising and information materials for a memorial award established in her name. We made the decision to do so, in part, because of our love (and that of our friends and family who joined us in this work) for her, as a way of keeping her, not alive, but somehow present. We were concerned she not be forgotten as so many people with intellectual disabilities (especially those who lived and died in institutions) were. The use of her image was thus rooted in our grief, in our need to keep her with us. I am not sure that, as of yet, I can comment upon the effects of this use (misuse?) of her image, although I am quite certain it could be (and would be) soundly critiqued. What I can say is that I do not know what Jen might have thought of all of this – either the use of her image (while living) in the service agency’s fundraising, or our use of her image in our fundraising activities after her death. And it is this (missed) conversation that has become increasingly important to me.

While I derive no comfort from this, I am not alone in having failed to ask. Persons identified as having intellectual disabilities have long been denied status as knowers – even as knowable (Winzer, 1997; Yong, 2007; Young & Quibell, 2000). The historical – and contemporary – subjugation of the knowledge of people with disabilities, effected through their exclusion from the category ‘knowers’, means they have not been given a voice in society to speak to their relationship to society, to how others perceive them, and to the space(s) they (don’t) occupy in society. They have not been given a voice or space to speak to how they experience and

understand themselves and the world in which they live. Consequently, they have been denied biographical lives, and have, in a sense, lived unlived lives. As orphans of history they have not, themselves, been permitted to leave a trace, a personal mark, on what is recorded in history as human achievement and expression (Corbett, 1996). As a group, they have had little, if any control over their ‘image’; little or no influence over how they are represented and thus understood. Insider accounts of labelled persons are, by and large, unavailable (Atkinson & Walmsley, 1999; Goodley, 1996; Linneman, 2001; Yong, 2007). For the most part, we have all failed to ask.

As Judith Butler (2004: xii) observes, vulnerability is unevenly distributed and it is these “differential forms of allocation that make some populations more subject to arbitrary violence than others”. Persons with intellectual disabilities, especially those with more severe impairments, have been defined by their attributes since time immemorial. The violence done to them is rooted in a perceived difference produced by a conception of absence – of intelligence, mindedness, reason, and thought – the absence of that which defines ‘human’. Of critical importance then is how, as a synecdoche, the referent ‘intellectual disability’ as a signifier of impaired or seemingly absent mindedness, perpetually serves to (violently) discount this group as knowers and to (irresponsibly) delineate them as ‘other’ to the extreme case. Deemed unable to know, we don’t ask and they are thus denied the opportunity to tell. Considered empty subjectivities, labelled persons are largely “spoken for” and “spoken by” the language of dominant (non-disabled) others (Felman, 2000). Both shared meanings and individual authorings of disabled lives are silenced (Corker & French, 1999).

My own reading of the literature reveals that attention – asking and listening – to personal (and collective) experience and meaning-making by people labeled intellectually disabled is at a

nascent stage. Largely influenced by an emerging self-advocacy movement, people with intellectual disabilities have only recently been granted the opportunity to speak *for* themselves (Dandaneau, 2001), and to begin to critically engage with notions of impairment, embodiment, and subjectivity, and with the internalization of social oppression and critique (Goodley, 2004), and to reveal just how much they have to say.

Is social work listening? Are social workers and social work researchers seeking out the thoughts, opinions, and experiences of people with intellectual disabilities? Asking in order to learn and inform practice? Social work(ers) and persons with disability are inextricably linked – there are few (if any) areas of social work practice that do not include people with disabilities and are not impacted by disability issues. Social work has, and continues to, define itself as a profession whose primary responsibility is towards oppressed people (as individuals and as members of social groups), “as located within a story of social advance, of the demonstration of a commitment to social justice, equality, and the struggle against oppression and degradation” (Leonard, 2001:3). As social workers, we understand that change is possible when we work with individuals and that radical change can happen when we listen to oppressed groups (Freire, 1970). Yet, the profession has been reluctant to become actively involved with, or to take up the cause of, people with disabilities, except in a medical or rehabilitation context (Oliver & Sapey, 2006). Our history of intervention is understood by many within the disability community to be a violent one, mired in functions of diagnosis, evaluation, measurement, inspection, control (Oliver & Sapey, 2006). Similarly, the corporeal otherness we think of as ‘disability’ has generally been overlooked in social work scholarship (French Gilson & DePoy, 2002; Mackelprang & Salsgiver, 1996): disability is “beneath notice” (Titchkosky, 2003:216). Breckenridge and Vogler (2001:349-50) exhort that “(a)n ethics and politics of disability are

crucial to the work of the university – pedagogically, theoretically, and institutionally”, and highlight the necessity (and concurrent difficulty) of reconfiguring knowledge using the lens of disability. The imperative to contribute to social work knowledge about intellectual disability – by seeking out the knowledge of labeled people – would, thus, seem inviolable.

One (among many) of the damaging consequence(s) of the historical exclusion of people with intellectual disabilities from the mainstream is that many non-disabled people have had no direct experience or relationship with a person labeled intellectually disabled, necessitating a turn to medicalized sources or cultural representations for knowledge; sources that, by and large, perpetuate notions of disability as tragedy and people with intellectual disabilities as unknowing and unknowable others. These factors combine to shape the meanings we attribute to people with intellectual disabilities: “Our knowing has limits simply because we are human beings who are struggling to know but always already enmeshed in ongoing systems of meaning” (Dandaneau, 2001:99). Further, the integration of new ideas and new language about intellectual disability is tempered by, or co-exists with, the history of intellectual disability, historical ideas and images that cast a shadow on our contemporary understandings (Dandaneau, 2001:107):

[W]hen they conjure the meaning of a child like Jamie, [they] imagine also the mongoloid idiots of the past locked in their institutions, remember the eugenics movement and see the disabled children today abandoned in Brazil, left in hospitals in Zimbabwe, or cared for by over-stressed parents in the lands of milk and honey” (Dandaneau, 2001:109).

It is from this intermingling that we form our own mental images of people with intellectual disabilities, mental images that are, themselves, visual and that derive, at least in part, from our viewing of cultural images of them. In our coming to knowledge about this other, we need to attend to the visual mental images we hold; we must engage in the (possibly difficult) ascent downward towards knowing (Cixous, 1993:5), the deconstruction of these visual mental images

and their cultural influences, before we can create other ways of knowing that take into account this embodiment. What if, as part of our social work thinking, we addressed the embodiment of these mental images in public photographs of people with intellectual disability?

Photographs afford a means, a starting point, from which to explore how we come to know persons with intellectual disabilities. Photographic images are intricately bound up with knowledge and understanding of the self and the other in contemporary culture, and, like language, provide a powerful means of defining individuals and social groups (Mauer, 2005; Newbury, 1996; Patton & Smith, 2001). The technological photographic image is “the real marker of the postmodern, able to trace out subjects’ experience as border lines between natural and artificial” (Artieri, 1996:56, in Harper, 2000:720), and to “alter what and how we see (even changing the nature of sight, reality, and imagination)” (Harper, 2000:720). As cultural images, photographs offer a measure by which to identify shifting social attitudes towards marginalized populations, as well as an indication of particular sites of resistance to change (Darke, 1998). Yet, “the interpretive ambiguity of photographs is inescapable; there is no such thing as a one to one correspondence between message intended and message received” (Cole & McIntyre, 2004:2; Berger & Mohr, 1982). As articulated by Derrida (1998:3), photographs can be understood as a “machine for making talk – inexhaustibly”.

For disabled people, self-identity and self-worth are situated in a broad field of re-presentation – a field in which photography is also implicated. Yet, photography is critically important to people with disabilities who are, most of all, conceptualized visually – in terms of the how they are seen (Darke, 1998; Garland Thomson, 2001, 2009; Newbury, 1996). Garland Thomson’s work, in particular, emphasizes the role of visual cultural representations in shaping, constructing, and producing disability (1997, 1998, 2001, 2009), in determining which subjects

can appear, how, where, and in what capacity (Corker & Shakespeare, 2002). The vast majority of public photographic imaging of disability can be described as stereotypical, disabling, and dysfunctional (Hevey, 1992). Phillips (2001) argues that what is missing, but is crucial, is the unique and valuable perspective that persons with disabilities bring to their own representations. Consequent to their production as a non-viable speaking subject (Butler, J., 2004), it is non-disabled others who, in writing onto the disabled body dysfunctional narratives, write away the stories, meanings, and signature of people with intellectual disabilities. The knowledge labeled people possess is excluded, made irrelevant, and our knowledge *of* them is both disabled and disabling. Inherent within photographic work is its potential as a vehicle for exploring and reconstructing understandings of disability, for de-centring representations, in an educational as well as cultural context (Clare, 2001, 2009; Newbury, 1996). Photography offers a means, an opportunity, or the circumstance by which we might ‘see’ productively or transformatively (Silverman, 1996).

It is the overarching concern of coming to know people with intellectual disabilities that encases and shapes this inquiry – what and how we come to know people with intellectual disabilities, and how our knowledge and means of knowing might be changed. Theoretically, this thesis draws from Emmanuel Levinas, critical disability theory, and Jacques Derrida. I am most strongly influenced by Levinas’ concern with our ethical responsibility to the alterity of the Other. Levinas offers me a way of looking differently at the question of social work responsibility, reframing responsibility as an attentiveness to the Other that is a welcoming, a hospitality, and that is, in effect, a response of social justice. Engaging with Levinas to consider the practices of photographic representations of people with disabilities, raises questions concerning the humanity and dehumanization of people’s lives effected in/by visual

representations. Understanding the image as an address, what is our responsibility to being so faced by the person within the public photographic image? How does one enact this responsibility, this non-indifference and attentiveness?

My understanding of ‘disability’ – as a construct and as lived experience – is shaped by critical disability theory and it is from this lens that I read the literature on social representations of disabled people. Regarding disability as a form of social oppression akin to racism, sexism, and heterosexism, critical disability theory locates the causes of disability, not pathologically within the individual, but in society and social organization (Frazee, Gilmour, & Mykitiuk, 2006), in the entrenched assumptions and practices of ‘ableism’. As such, it demands an analysis of the mechanisms and holders of power, in this case, in photographic representations of intellectual disability which, historically, have not been kind to people so labeled. This perspective powerfully informs my methodological decisions in this inquiry, ethically directing my attention to responsibly seeking the perspectives of people with intellectual disabilities themselves.

Addressing both the politics and ethics of representation, I borrow from Derrida’s (1998) thesis, *The Right of Inspection*. In this work, Derrida questions what happens in the process of “inspecting” public photographic images – the “right to look”, to “take” a photograph - and of just who is/should be entitled to “inspect”. Tying into a critical disability lens, the emphasis is on what is inscribed in the photographic images and how we can deconstruct these images to both tremble the inscriptions and re-inscribe otherwise. Linking Derrida to Levinas, I consider how the face of the Other is admitted into public representation, and how being rendered ‘faceless’ (or a de-humanized Other) authorizes violence. The emphasis is on disrupting the boundaries of what faces can and cannot appear in public spaces, what can and cannot be known. The ideas in this thesis, then, coalesce around two central themes: the right of inspection and the

responsibility of inspection.

I use critical disability, Derrida, and Levinasian lenses to inform an ethically responsible social work response: looking at how, through an inclusive research methodology, to give voice to the knowledge, perspectives and experiences of people with intellectual disabilities as they contend with public photographic representations; and how to use the knowledge gained from this interaction as a means of interrupting what is known about them, to make space for new knowledge and for alternative social work interactions with people so labeled. Recognizing the value of what people with intellectual disabilities have to say, the study provided a space for labeled people to critique public photographic images and challenge the taken-for-granted ‘truths’ of disability inscribed in them, and work towards more complex and nuanced understandings of ‘intellectual disability’. The questions being asked in this inquiry are as follows:

- 1.) How can/do photographic images serve to represent or mis-, dis- or dys-represent, people with intellectual disabilities, thus influencing how we come to know, what we know, and what we tell others about them?
- 2.) How would people with intellectual disabilities, themselves, interpret and respond to these representations and means of knowing?
- 3.) How might they use photography to disrupt/destabilize/interrupt/problematize these dis-abling representations, this knowing and telling? And use these alternatives to stimulate/facilitate/permit other/multiple ways of knowing?
- 4.) Do we, as social work(ers), have a responsibility to do so? Does our ‘right of inspection’ also entail a ‘responsibility of inspection’? What are the ethical implications to social work(ers) of these ways of knowing and telling?

Stiker articulates the ethical, political, and affective elements necessary (and inevitable) in all studies of disability. In that disability is never a neutral subject, “(w)hoever addresses disability...is engaged in its study in a personal capacity”. He notes, too, “(t)he issue of responsibility is likewise implicated in the study of disability” (1999:1). Reminding us that people with disabilities, their families, their friends, are among us and also among our readers, he

suggests that “every effort at theorizing also enters into a relational context, a communication” (Stiker, 1999:1). As an encounter with disability, and with disabled people, this study, then, is intended as an engagement with the question of our social work responsibility to people with intellectual disabilities.

I have organized this study into four main sections. The first section frames the study. The second section is my re-presentation of the work done by the people with intellectual disabilities who answered my invitation to participate. Section three presents the analytic chapters of the study. The fourth, and final, section concludes the study.

Section I, *Framing the Work*, contains six chapters. In this first chapter, I share the origins of this study, thus locating my (researcher and parent) Self in the work and providing the backdrop to the overarching concern of the study and the research questions. In Chapters 2 – 5, I elaborate the theoretical frames and re-view the literature that combine to shape this inquiry. In Chapter 6, I introduce the persons with intellectual disabilities who came together to complete this work, and address the ethical and practical challenges involved in my approach to this research.

Section II, *What’s Wrong With This Picture?*, I have similarly grouped into six chapters. In Chapter 7, I present the public photographic images the participants chose to work with. In Chapters 8 -11, I re-present their work with these images. Chapter 8 is focused upon issues of (un)care as represented in photographic disability imagery and as experienced by people with intellectual disabilities. Chapter 9 revolves around the notion of ‘weightlessness’: intellectually disabled people’s perceived and felt (lack of) power and influence effected in and through visual representation. In Chapter 10, I discuss the multiple otherings of people with intellectual disabilities in public imaging and imaginings of disability. And, in Chapter 11, I speak to the

participants' ambivalent relationships to intellectual disability and disability imagery. Chapter 12 is structured as a photo-gallery, re-presenting the original public photographic images alongside the participants' transformations of these images.

Section III I have entitled *(Un)Wounding Representations*. In this, the analytic core of this thesis, I take up the constructs of the right and responsibility of inspection. In Chapter 13, I explore the participants' understandings of the right of inspection and the right to self-representation. Chapter 14 hinges upon the question of the responsibility of inspection. In this chapter I discuss non-disabled ethical responsibility to the disabled Other in the image, and the responsibility/response-ability the intellectually disabled participants perceived themselves to have. In Chapter 15, I address both the right and responsibility of inspection in terms of the participants' transformative work with the images.

In Section IV, *Make Me Think Me*, I discuss the implications of this project for social work and speak, as well, to the work that has arisen from this study.

Chapter 2 – Responsibility and the Im/possibility of Social Work Knowing

Introduction

Social work, as a profession, is preoccupied with coming to know, with a will to knowledge, as a means of intervening in people's lives. Indeed, using social work knowledge to 'help' is generally understood to be the profession's primary responsibility (Rossiter, 2006). The central assumption of many ethical (and social work) theories is that, in our will to knowledge, we have the power to imagine ourselves in the place of the Other and to make judgments on behalf of the Other (and structure our interventions, our 'help') on that basis (laCaze, 2002; Rossiter, 2006).

Emmanuel Levinas' work on the ethical responsibility to the Other, troubles social work responsibility. Levinas' notion of alterity runs contrary to these assumptions, and his idea of an ethical responsibility to the alterity of the Other¹ significantly influences my work. For Levinas, the alterity of the Other speaks to the uniqueness of the Other, a uniqueness which means that we can never, completely, know the Other. In this sense, difference does not create alterity, rather alterity is what determines difference. We are each unique, not as a function of an attribute or a characteristic (such as impairment/disability), but as a being particular in his genus and different because s/he is not me (Levinas, transl. Robbins, 2001a). A Levinasian responsibility, then, is a relation with the Other that does not involve "normalizing knowing" (Saul, 2001:39); or the violent totalizing, self-valuing, empathetic identification of the disabled Other as "same" (Taylor, 2001) with its erasure of, or indifference to, different ways of being and to the very real needs posed by disability - a collapsing of myself and the Other - what Levinas regards as a tragedy in solitude (Levinas, transl. Schmitz, 2001b). Nor does it allow for the reductive enfolding of all

people with disabilities into a single category: de-humanized other, a categorization that authorizes violence (Butler, J., 2004). In a Levinasian scheme, the relation to the Other is a humanization of the Other that is tethered directly to their alterity. In that the ethical demand emerges from this humanization of the face of the Other (Butler, 2005), ethical action, and the ethical subject, cannot exist without an adequate recognition of alterity (Duncan, 2001; Levinas, transl. Smith & Harshav, 1998). Theorizing social work from this position requires us, as Wendell (1996) challenges, to re-think disability as devalued difference, to re-think that which we think we know.

What would it mean then, in practice, to value disabilities as differences? It would certainly mean not assuming that every disability is a tragic loss or that everyone with a disability wants to be “cured”. It would mean seeking out and respecting the knowledge and perspectives of people with disabilities. It would mean being willing to learn about and respect ways of being and forms of consciousness that are unfamiliar, and it would mean giving up the myths of control and the quest for perfection of the human body. (Wendell, 1996:84)

Others writing from a Levinasian frame acknowledge that the saying (of ability (DeShong, 2008), of subjectivity (Rossiter, 2006)) will always exceed, and undo our discursive grasp of, the said (Simon & Eppert, 1997). Apprehending the disabled Other this way moves the study of disability beyond an enlightenment modernist (and ableist) project of integration/inclusion that understands ability/personhood/subjectivity only as that which can be articulated, and, perhaps more importantly, as that which can be readily understood as (at least, similar to) ‘normal’ or ‘typical’. In redefining the difference of disability as integral to the human experience (Stiker, 1999) ‘normal’ articulation (and being articulated as ‘normal’) is no longer the limit of thought, expression, or action/politics. This im/possibility of disengaging the possible (the articulated) from the impossible (that which cannot be articulated) (DeShong, 2008) connects Levinas’ saying of our response/responsibility to the saying of disabled knowing, and of disabled being.

In his engagement with Levinas' work and dis/ability, DeShong (2008ⁱⁱ) returns alterity to a question of value. Disinclined to simply make more inclusive our definition of "able"ⁱⁱⁱ(DeShong,2008), and contradicting the long-dominant philosophy and related practices of normalization in the field of intellectual disability, it entails a belief that the "two-ness", the "non-unity", has value in and of itself (Levinas, transl. Schmitz, 2001b). Our responsibility to the Other is thus tied both to the recognition of the Other, and to her/his alterity or uniqueness (Levinas, transl. Robbins, 2001c), to her/his signature (Cornell, 1992). In our encounter with this Other who takes us to the limits of our conceptualizations, mis-recognition is possible and we can experience the Other as non-identical (Cornell, 1992), difficult to understand but not dis-valuable.

Because for the first time, the only time, someone wasn't trying to fix him. They were just describing him. There was no judgment or fear. It was just very accepting. And I do think it was a turning point for me. Instead of trying to fix Walker or make him better or diagnose him or see what was causing his state, it was just what and who he is. This is what he's doing. It wasn't a triumph or a tragedy. It just was. (Brown, 2008, part 2, chapter 5:6)

The Responsibility of the Address

Levinas writes: "From the start, the encounter with the Other is my responsibility for him" (transl. Smith & Harshav, 1998:103). For Levinas, ethics replaces ontology as the first concern of philosophy. His conceptualization of this ethical responsibility to the Other is understood by me as an imperative, an originary response of "one-for-the-other" effected prior to any consciousness, volition, knowledge, judgment, or action, that would enfold the Other up in my own terms. My proximity to the Other who stands before me, who "faces" me, dictates my responsibility to a "non-indifference" with regard to this Other who, before all reflection, concerns me, addresses me, and demands my attention in such a way that I am not interchangeable or replaceable (Diprose, 2001; Levinas, transl. Smith & Harshav,1998). The face

of the Other, being faced by the Other, is the means by which the Other addresses and makes a moral demand upon us (Butler, J., 2004). The face, then, is the face of the Other, and also the ethical demand made by the Other (Butler, J., 2004), it is the trace of our already being in an ethical relation with the Other (Perpich, 2008). To not hear or to refuse the ethical address is to efface or evacuate that which is most human about the face for Levinas: de-humanization thus stems from being rendered face-less (Butler, J., 2004). I am responsible not by virtue of my actions, not by the causality of ‘doer’ and ‘deed’ but, rather, by virtue of my relation to the Other. It is a susceptibility to the Other, an unwilling, unchosen susceptibility that is the condition both of my responsiveness to, and my responsibility for, the Other (Butler, 2005). This for-the-other in the saying of my responsibility is not a conscious, thematizing intentionality demanding reciprocity (Levinas, transl. Lingis, 1991) but, instead, a sincerity, an affective openness to the Other in the saying of my “here-I-am” response (Diprose, 2001). It is a responsibility that apprehends both the interdependence and the precariousness of life that is represented in the face of/facing by the Other (Butler, J., 2004). The realization of this vocation of being-for-the-Other ruptures the ontological imperative of *conatus essendi*, creating the possibility of dis-interestedness towards a rational preservation of Being, of the self, in favour of an awakening to the priority and alterity of the Other. Perceiving the limits of reason as the sign of our humanity (Butler, 2005), it re-positions me as an irrational animal or as rational according to new reasons (Levinas, transl. Schmitz, 2001b)^{iv}. This notion of responsibility towards an ‘unknowable’ Other is, I feel, eloquently expressed in the words of a young man with autism who is unable to communicate with spoken words:

its so sad for me that nobody understands me but it is important for a lot of people to understand me a bit ...and the others don’t take any trouble with a person like me any more its enough to drive one to despair (Sellin, 1995:78)

Derrida suggests that Levinas' expansive work is, at heart, dominated by a single thought – this understanding of ethics as a relationship of infinite responsibility to the other person (Bernstein, 2002). He describes the movement of Levinas' thinking as a wave, the same wave, perpetually returning and repeating its movement with deeper insistence (Critchley, 2002). But, while other influences in his work are certainly evident (Critchley, 2002), there appears to be agreement that Levinas' life and work were dominated by the atrocities of the twentieth century, the Shoah and loss of most of his family in particular (Bernard-Donals, 2007; Bernstein, 2002; Critchley, 2002; Putnam, 2002), and by his worry that should we fail to ground our intersubjective relationships in an ethical relation with the Other, then “the worst might happen, that is, the failure to acknowledge the humanity of the other” (Critchley, 2002:13). Humanity, our own and that of the Other, lies in this ethical relation with the Other (Butler, J., 2004). Indifferent to the Other (Levinas, transl. Smith & Harshav, 1998), such atrocities become possible once again (Bernstein, 2002). The only adequate response is our infinite willingness to be available to and for the Other (Putnam, 2002).

Responsibility and Attentiveness

For me, Levinas' articulation of *Zakhor*, as a relationship and a communication practice, an injunction and a responsibility, is a useful means of articulating social work's responsibility towards the stories, memories, and knowledge of Others (Simon, 2000). As Simon writes, *Zakhor* is a component of a commandment that obligates us, as witnesses, to the specificities of four responsibilities towards these testimonies. These are: to learn and study them (listen and read), to teach them (speak and write), to keep and preserve what has been learned (repeat lessons learned, find new questions to ask) and to remember them. The responsibility of *Zakhor* is fulfilled when “these activities are consolidated into a vigilant, interminable attentiveness to a

‘saying’ that addresses one with its demand to ‘remember’” (Simon, 2000:11).

It is the posture of attentiveness that is so important here. How does one attend to the experiences of others? How does one open oneself to an Other and enact one’s non-indifference? To fulfill the responsibility Levinas defines, one must travel beyond spontaneity, beyond determinate interpretations or a consuming recognition of the Other on my own terms (Duncan, 2001) which would allow me to abjure any ethical requirement towards change, destabilization, or learning (Simon, 2003). One must move, instead, towards a responsibility that provokes and embodies a "summoned kavannah", an attentiveness or wakefulness, a form of presencing, a being-for-an-other, that is, for Levinas, a "sensitivity" (Simon, 2003:9). Sensibility entails vigilance in one's orientation to the said and to the saying of the Other, and, also, attention to how one is attending (Simon, 2003). These doubled moments of attentiveness (informational and reflexive) are what link remembrance and learning (Simon, 2004). Listening, thus, is a way of thinking (Simon & Eppert, 1997). Corker’s articulation of “sensing disability” is similar to Levinas’ conceptualization of an opening to the Other, a vigilant and vulnerable sensitivity to the Other. She posits that it is by this sensitivity towards disability that dis-valuation can be countered: attending to and dialoguing across difference at a level of signification, re-situating narratives of disability as mutually constitutive realities, opening oneself to the kinds of possibilities that can be realized (2001:46-7). Solomon (2007) articulates a similar presencing in her call for a careful [or care-ful?] listening^v in social work, a listening that is, as Levinas suggests, attentive and, in Solomon’s language, intentional.

Wounding Exposures

Levinas’ sensitivity invokes a vulnerability within which "knowing, being's disclosure to itself, marks a break with the thematizable, with the abstractions within which one grasps an

understanding of who it is that addresses you and what might be the substance and import of his or her message" (Simon, 2003:10)^{vi}. Thus, acutely aware of the alterity of the Other, a vulnerable sensibility demands my exposure to my own unknowing, to a wounding that obligates me to respond and to be accountable (in ways I cannot predict or control (Butler, 2005)) even as my response-ability is challenged by this very alterity (Simon & Eppert, 1997). "This is sensibility as *kavannah* which establishes proximity, not as a state, a repose, but a restlessness, a movement toward the other in which one paradoxically draws closer when vigilant of one's infinite distance from the other" (Levinas, 1998a:82, in Simon, 2003:10). As articulated by Henri Nouwen (1997:42), a theologian and pastor who lived for many years with persons labelled severely intellectually disabled in the intentional community of L'Arche Daybreak:

I didn't know him. I didn't know what he expected of me. I didn't want to upset him. And in front of the others, I didn't want to make a fool of myself. I didn't want to be laughed at. I didn't want to be a source of embarrassment.

And further (p.43-4):

because he did not speak or respond to anything I asked him...I wondered if he even recognized me. How would I get to know him? What, I asked myself, was he thinking, was he feeling, was he sensing? What was his experience with me?

As an unconditional hospitality to the Other (Simon, 2003), a Levinasian ethics of responsibility is, then, a responsibility towards an understanding that is rooted in 'not knowing', in the tension of responding to, and being respons-ible and response-able for, an Other who can never be *completely* known. In and of itself, this for-the-other response is not knowledge. Responsibility is disengaged from knowledge and is, instead, a sincere and affective opening to the other (Levinas, transl. Smith & Harshav, 1998). It requires or demands a relational stance towards this infinitely unknowable other, an ethical engagement arising from the sense and principle of *relation* with the Other^{vii} as opposed to reference to knowledge or the universality of a law

(Levinas, transl. Robbins, 2001c). To consider this in the context of this project, let me turn, once again, to Rossiter's questioning of social work from a Levinasian lens. My (social work) responsibility is based, not upon the givens of (potentially violent) knowledge(s) determined by the contemporary gaze (e.g., dominant discourses of disability and social work) which apprehends them, nor by prevailing theories of the day or institutional mandates, but on what is required *of me by* the person facing me. Not only does my response *not* depend on social work knowledge, but my "obligation to the mystery of others is to the constant jeopardy that mystery poses to our knowledge and comprehension as professionals" (Rossiter, 2006:142), thus keeping open the space of social work.

Rethinking disability and social work with disabled people is the undoing of a way of knowing (Davis, 2002). Following Levinas, Butler proffers an ethical valence to my (social work's) unknowingness: "the wound testifies to the fact that I am impressionable" (2005:84), and, read as a rupture or point of departure, the wound becomes a condition of possibility, an avenue by which to effect change (Simon, 2003). Responding to the Other, fulfilling one's ethical responsibility to the Other, is often an opportunity for new knowledge since each experience of the Other is the beginning of new concepts, of new thinking (Levinas, transl. Schmitz, 2001b); each wounding a movement towards a critical and a risk-laden learning (Simon, 2004). Payne offers a parallel, the possibility of understanding "social work [as] an interactive process in which client changes worker *and* the nature of social work *and* therefore changes also the theory of social work" (1991:15). Wounded (dis-abled) by the testimony of this Other, cognizant of my own unknowing yet open to change, to witnessing, listening and learning, writing and telling, it is, perhaps ironically, I (the social worker) who must first become "inhuman" (in Lyotard's (1991) sense of our native, childhood indeterminacy in which the body, in addressing and being

addressed, constantly strives towards growth), and “irrational” (Levinas, transl. Robbins, 2001c), in order to become more fully human.

Perhaps most importantly, we must recognize that ethics requires us to risk ourselves precisely at moments of unknowingness, when what forms us diverges from what lies before us, when our willingness to become undone in relation to others constitutes our chance of becoming human. To be undone by another is a primary necessity, an anguish, to be sure, but also a chance – to be addressed, claimed, bound to what is not me, but also to be moved, to be prompted to act, to address myself elsewhere, and so to vacate the self-sufficient “I” as a kind of possession. If we speak and try to give an account from this place, we will not be irresponsible, or if we are, we will surely be forgiven. (Butler, 2005:136)

Taking this argument even further, the “difference” within the “alterity” of the Other actually serves to maintain the possibility of a response of “non-indifference” with regard to the Other (Levinas, transl. Robbins, 2001c) – even a seemingly incommensurable disabled Other. The fact that I may perceive this disabled Other as being radically different from myself – an unknowable (abnormal?) Other whose recognition serves only to define my own (normal?) identity (Corker, 2001; Kratz, 2002), or a menace that threatens my own existence (Butler, J., 2004) – and that I may even be (excessively?) disturbed by this, does not excuse or absolve me from responsibility for this Other. Irrespective of my own discomfiture, it actually predicates and makes un-refusable this (heretofore largely ignored by social work) responsibility – my indifference is shattered (Levinas, transl. Smith & Harshav, 1998). Un-able to control or consume this Other as same, or to disregard, discount, or expel her/him as being too different, in excess of that which, in our desire for sameness, we can accept we are propelled towards a different type of response. Such an engagement is not designed to create a new ‘normal’, but to extend (indefinitely?) the margins of that which we value (DeShong, 2008).

Writing about his relationship with his son who was born with Down syndrome, Berubé says:

Jamie has no idea what a busy intersection he's landed in: statutes, allocations, genetics, reproduction, representation – all meeting at the crossroads of individual idiosyncrasy and socio-political construction. “Value” may be something that can only be determined socially, by collective and chaotic human deliberation; but individual humans like James are compelling us daily to determine what *kind* of “individuality” we will value, on what terms, and why. Perhaps those of us who can understand this intersection have an obligation to “represent” the children who can't; perhaps we have an obligation to inform our children about the traffic, and to inform the traffic about our children. As those children grow, perhaps we need to foster their abilities to represent themselves – and to listen to them as they do. I strongly suspect that we do have those obligations. I am not entirely sure what they might entail. (1996: xix)

This thesis is an exploration of what those obligations entail. The introduction of the face (of labelled persons) is the entrance of the ethical into (social work/research) experience (Duncan, 2001). Faced by the Other, I cannot refuse the address, the call for response. In enacting my non-indifference, my (summoned) attention is required. Social work practice and research is thus a means of welcoming and paying attention, of becoming informed and of informing both Berubé's “children” and his “traffic”. Beginning from a position of unknowing, it is, simultaneously, a relational stance that affords the opportunity to question how to ethically and responsibly respond to the address or touch of, and to engage with and learn from, the Other labeled intellectually disabled. As such, it is a movement between being with the Other and recognizing the Other as an individual and a member of an oppressed group. More specifically, this research becomes a process by which to rethink disability and our relationships with disabled people: a chance to look at how to seek out and give voice to the knowledge, perspectives and experiences of people with intellectual disabilities as they contend (in this case) with the limits and consequences of public photographic representations; and how to use the knowledge gained from this interaction as a means of problematizing the boundaries of these public representations, interrupting what is known to make space for new knowledge and alternative ways of knowing and being and being with. In this way, it becomes a responsibility for social justice. For

Levinas, the first question of the interhuman, of this relationality, is a question of justice (transl. Smith & Harshav, 1998). As a consequence of interpreting social work as a vocation of being-for-the-other, as a preoccupation with the Other, it, too, is (re)situated (Chambon & Irving, 1999; Leonard, 2001) as a responsibility for (social) justice.

Chapter 3 – Re-thinking Disability

Introduction

Let me turn now to another theoretical strand from which to approach the questions being posed in this thesis. Critical disability theory is very much about re-thinking disability and our relationships with disabled people. Singularly focused on problematizing that which we think we know, it is pre-occupied with coming to an understanding of relations of power and with pointing to the violence inherent in established ways of knowing and responding to people with disabilities. As with a Levinasian approach, working from this theoretical lens infers a response and a responsibility, although, as I will address later in this section, these differ in some respects from a Levinasian understanding of our ethical responsibility to the Other. The obligation to forefront heretofore silenced and subjugated disabled voices is regarded the primary avenue by which to effect new learning, transformations, that work towards social justice.

Re-thinking Disability as Oppression

Theorizing disability from a critical lens emerges from a relatively new discipline, (critical)^{viii} disability studies. While it is not without its detractors or challenges from other social-contextual approaches (Shakespeare, 2006), the social model of disability still underpins much contemporary critical theorizing of disability, including my own. Developed in opposition to the medical or individual deficit model of disability that figures disability as a medical problem, an abnormality located on or within the individual, that must be fixed, cured or eliminated (Davis, 2002; Fritsch, 2004; Millet, 2005; Mitchell & Snyder, 2001; Titchkosky, 2003), the social model understands disability as “a socially invented category that primarily reflects the state of mind of those people who use the concept, not of those who allegedly have it” (Vehmas, 2002:210). This model is an organic one which, in a postcolonial sense, arose from (and continues to inform) the social

movement known as the disability movement. It is explicitly ideological and in the service of an unambiguous political agenda – emancipation from ableism.

Contextualized in this way, ‘disability’ is understood as constructed, and as the experience of oppression (Corker & Shakespeare, 2002; Oliver & Sapey, 2006; Thomas, 2004; Whalley Hammell, 2006). As a heuristic device, the model problematizes society rather than the individual, redefining disability not as a medical category but as a political one (Frazee, Gilmour, & Mykitiuk, 2006); not as a biological phenomenon but as a social relational one (Corker & Shakespeare, 2002; Thomas, 2004). It has been instrumental to a growing analysis of the multiple factors, influences and forces involved in how we have, and continue to, define, understand, and respond to disability. Regarding disability as either materially produced (the product of disabling barriers and material relations of power) and/or discursively produced (emphasizing the role of ideas, attitudes, language, and culture in shaping, constructing, and producing disability), disability is understood to be a constructed category of abjection and dysfunction. The emphasis, then, is on challenging the assumptions of this ableist production (Goodley & Roets, 2008; Parton, 1999; Vehmas, 2004). Unveiled is a pervasive ableist power that interacts dynamically with forms of knowledge that capture and make intelligible the disabled body (Bérubé, 1999; Campbell, 1999; Michalko, 2002), rendering people with disabilities ‘knowable’ and determining, not only how they are to be understood and what is to be done to them, but what is desirable to be, and to do. Troubling essentialist understandings, a social model understanding highlights instead the common, complex experiences of oppression, marginalization, discrimination, exclusion and stigmatization that pervade all aspects of life for people so defined (Barnes, 2003; Campbell, 1999; Frazee, et al., 2006; Williams, 2001; Yong, 2007).

Paralleling theories of other socially marginalized groups, the perception of and responses to

biological differences are understood in the social model, not as fixed, universal or transhistorical, but as contingent: the ways that we come to understand disability; the categories and concepts that we use; who, where, how and in what capacity someone is understood to be ‘disabled’, are each historically and culturally specific (Corker & French, 2002; Marks, 1999; Vehmas, 2004; Yong, 2007). There is no stable, a-culturally constant, or ‘natural’ body: ‘natural’ is merely the script of culture writ large upon the body (Michalko, 2002). As such, ‘disability’ is revealed as an unstable, uncertain category that serves to construct normative conceptualizations of ‘human’, ‘ability’, and ‘privilege’. Troubling, confronting, and opposing taken-for-granted notions of disability, a social model perspective recognizes that “(c)hange can come from the realization of the precarious nature of established ways and by inviting the development of alternatives” (Chambon, 1999:70).

Troubling the Social Model

The social model of disability has come under attack on a number of fronts and, as an “ever-evolving criticality” (Kinchloe & McLaren, 2005:303), much second and third wave disability theorizing is moving beyond a strict, social model understanding. Criticism has been directed at the model for its apparent insufficiency in addressing the complexity and multiplicity of factors involved in the production of disability. The intersectionality of race, gender, class, sexuality, or other social markers is largely ignored (Clare, 1999; Marks, 1999). It does not yet sufficiently address the role of culture, or experience embedded in the language of disability (Kasnitz & Shuttleworth, 2001). Similarly, it can be read as an urban model, one that ignores the problems created by “mud and sand, snow and cold, trees and vegetation, rough ground, unpaved roads, mountains and hills: problems that will present insurmountable barriers in even the most just society” (Whalley Hammell, 2006). It has long been recognized to have an overly narrow focus

on mobility impairments and, as is most relevant here, its consequent lack of attention to persons with intellectual disabilities is a disheartening flaw^{ix} (Goodley, 2001; Shakespeare, 2006; Yong, 2007). Goodley recalls the words of one self-advocate who remarks: “People with ‘learning difficulties’ face discrimination in the disability movement. People without ‘learning difficulties’ use the medical model when dealing with us” (2001:210). Another unfortunate result is that social work epistemology thus remains slanted by an overwhelming preponderance of research activity that continues to be service-based, and to emphasize individual functioning and a deficit understanding of intellectual disability. A critical disability approach to intellectual disability is only beginning to emerge (Goodley & Roets, 2008).

People with intellectual disabilities: Included or excluded?

(I)ntellectual disability is *not* just a theoretical construct; rather intellectual disability is a difference that makes a difference. (Yong, 2007:113-4). People with intellectual disabilities confound a traditional social model understanding. Their ‘lack of fit’ with the model is most obvious when we examine how the social model understands and approaches the distinction between impairment and disability. *Impairment* is (problematically) defined as a ‘defect’ of the body (e.g., Down syndrome), whereas *disability* is regarded as a form of disadvantage (social, economic, political, material) imposed on top of one’s impairment – a disadvantage that could be eliminated (Fritsch, 2004).

Articulating the difficulty, Goodley & Roets write: “‘Impairment’ is a tricky issue. For many, this word symbolizes social death, inertia, lack, limitation, deficit and tragedy” (2008:239).

Understood in an ableist conceptualization as a sign of inferiority that conflates biological worth with social worth, impairment is used to justify discrimination (Williams, 2001). In an effort to downplay biological difference to achieve equity in social and political terms, a social model

sometimes disavows the significance and effects of that difference, of impairment (Corker, 2001; Jeffreys, 2002; Marks, 1999; Thomas, 2007; Yong, 2007) and, at times, deliberately excludes the phenomenology of embodiment (Hughes & Paterson, 1997; Goodley & Roets, 2008).

While quite comfortable critiquing, for example, the disabling effects of cultural photographic imagery, many social model theorists are reluctant to address (or even admit to) the potentially limiting and restrictive effects and individual experience of impairment. The polar categorization of (natural) impairment and (social) disability privileges the ‘doing’ dimension of disability over its ‘being’ dimension (Thomas & Corker, 2002) and has resulted in impairment being under-theorized. In its efforts to demedicalize disability, the social model has at times rendered the naturalized impaired body as the exclusive jurisdiction of medical interpretation. One part of this dichotomy is valorized (disability) while the other is marginalized, silenced, or denied (impairment), thereby producing distinctions of value and power which are not acknowledged. This bifurcation simultaneously suggests that ‘people with impairments’ and ‘disabled people’ are very different things linguistically, politically, and theoretically (Corker, 2001; Corker & French, 1999; Tremain, 2002). A telling example is found in the long-standing debate on language^x. One argument holds that the language ‘disabled people’ is politically more powerful, highlighting as it does the disablement imposed upon the impaired body by societal structures, systems and ideologies. Others – primarily people with intellectual disabilities and their allies – proffer that people first language, i.e., people with disabilities, works to humanize people with disabilities, to foreground abilities and their similarities to non-disabled people over their impairments (Titchkosky, 2001). The preference of self-advocacy organizations, such as *People First* here in Canada, is plain.^{xi} Further, by conflating the variety of disabled people’s experiences, the social model is understood to paint ‘disabled people’ as a homogeneous group

sharing a singular experience of oppression (Hughes, 2004; Shakespeare, 2006).

If, as the social model suggests, disability is (entirely) socially created /constructed, what happens in this model to people with intellectual disabilities (and to those with other impairments) whose differences may not be readily amenable to, or completely alleviated by, social, political, economic or linguistic change? The differences that disability labels try to name do not necessarily go away simply because we no longer name them (Yong, 2007). Ramps, more money, new terminology, or even more positive cultural representations and attitudes do not necessarily eradicate the difficulties that may be created by an intellectual disability. And, while we do have a moral and political imperative to identify and remove barriers, to effect these types of changes, this is an insufficient response. Jeffreys (2002) argues against the implied omnipotence of cultural constructions of disability, suggesting that an understanding of the human body as no more than a cultural fiction that can be re-constructed is inadequate to explain how the body may very well resist. Some extraordinariness refuses to be hidden or cured. It is, at the very least, naïve and disrespectful (Kittay, 2001), and some contend it is ridiculous (Whalley Hammell, 2006), to ignore the realities of impairment for people with (especially more severe) intellectual disabilities. Such corporeal silence reproduces a victimology of disability (Campbell, 1999). It also works to silence in other ways – devaluing and foreclosing different, embodied ways of knowing, and of articulating experience.

There is growing criticism that the impairment/disability classification scheme is illusory, oppressive, and exclusionary – little more than a chimera (Shakespeare, 2006; Thomas & Corker, 2002). The two interact to produce individual and collective meanings of ‘people with disabilities’ (McIntyre, 2003; Snyder & Mitchell, 2006; Wendell, 1996). Using a Foucauldian lens, Tremain (2005) argues that the category of impairment is not value neutral, nor merely

descriptive but, like disability, is also discursively constituted and maintained by disciplinary knowledge and power, and by governmental practices and political arrangements (see also Fritsch, 2004; Hughes & Paterson, 1997; Thomas & Corker, 2002 who make this point along different lines). Vehmas argues further that this absencing of the body, the lack of attention to impairment, is especially problematic in that it fails to recognize that the core concept of *both* disability and impairment is an ethical one (2004), and to prioritize disability over impairment is thus unethical, unacceptable.

Bringing back the body (differently).

In my own theorizing, I am drawn to incorporate feminist disability critiques alongside a social model of disability. Such critiques, drawing upon socio-relational models of impairment/disability are concerned not to erase subjective experiences of the (impaired) body. They open up impairment/disability debates by arguing that the very real “experience”, “inconvenience”, and “oppressive” aspects of impairment are left out of a social model (Campbell, 1999; Clare, 1999; Corker & French, 1999; Frazee et al., 2006; Goodley & Roets, 2008). “(D)isabled bodies must not remain unexplored in critical discourse”^{xiii} (Frazee et al., 2006:226). Any theory of disability must address the ethical, psycho-emotional, and epistemic issues of living with impairment, and with conceptions of the disabled self: it must take into account the personal as well as the social. Such a view is not a return to essentialism, the understanding of the social category ‘ability’ as “coherent, in the body, “real”, consistent, or homogeneous” (Fine & Weis, 2005:67; Hughes, 2004). Nor does it cast embodied difference as ‘lack’ (Garland Thomson, 1997). It refigures ‘impairment’ as both body and subjectivity. It has a physical dimension (thus allowing for inclusion of the ways in which the impairment, itself, can be limiting) and, at the same time, is also socially constructed from this biological reality and

can, thus, become (more?) ‘real’ (even if resisted) inside both the individual and institutional life, yielding dire social, political, and economic consequences (Fine & Weis, 2005; Fritsch, 2004; McIntyre, 2003; Shakespeare, 2006; Wendell, 1997).

Weaving in feminist and social-relational models of disability broadens and extends the social model to consider other dimensions of socially imposed restrictions (Goodley & Roets, 2008; Shakespeare, 2006; Thomas, 1999), restrictions which:

operate to shape personal identity, subjectivity or the landscapes of our interior worlds...include not only a concern for what “we do” and “how we act” (are prevented from doing and acting) as disabled people, but also a concern for “who we are” (are prevented from being), and how we feel and think about ourselves...This “inner world” dimension of disability is closely bound up with socio-cultural processes which generate negative attitudes about impairment and disability, and sustain prejudicial meanings, ideas, discourses, images and stereotypes. These impact upon disabled people in diverse ways and can lodge themselves in their subjectivities, sometimes with profoundly exclusionary consequences by working on their sense of personhood and self-esteem (Thomas, 1999:46, 47-8).

Like other feminist theorists, Thomas (1999) regards as crucial the need to consider and learn from personal experience of impairment, conceptions of the disabled self, and psychological experiences of internalized oppression and discrimination, from “the intra-psychic dynamic of environment, body and psyche” (Goodley & Roets, 2008:242). Important then is unburying the ways in which people with disabilities are made, uncovering the social worlds of people with disability, and attending to bodies that are inscribed by history – bodies “infused by anamnesis that recalls the past, present and future” (Campbell, 1999:71). In this way, a feminist perspective helps in “destabilizing the meanings of embodied differences and identifying sites where those meanings seep into other discourses... it provides for articulating the particularity of identity and its materiality as well” (Garland Thomson, 1997: 284).

Returning to questions of political power, this perspective does not ‘disable’ advocacy and activism. Rather than depoliticizing ‘disability’ (Goodley, 2006), such a view extends the politicization and activism of people with disabilities: disability is thus understood simultaneously as a personal and a public issue, as involving both hurt and prejudice (Williams, 2001), and as an embodied site of resistance (Beresford, 2006; Snyder & Mitchell, 2006) – the personal is political (Kittay, 2002; Ruddick, 2002). The meaning of ‘impairment’ is transformed from a purely individual issue to a site of social and political debate and activism (Goodley & Roets, 2008; Hughes, 2004).

As I wrote much earlier in this chapter, the responsibility explicated by a critical approach to disability is a political one. Underlying a social movement, it is at its core a responsibility towards an entire (and very large and exceptionally diverse) group whose members are understood to all require the same thing. The response itself has been clearly articulated: emancipation from ableism. Addressed by people with disabilities, social work is thus asked to do something that is on the one hand very specific – combat and overturn ableist impositions – but which is, on the other hand, so broadly stroked as to be impossible. The (re)entrance of the body into critical disability theorizing would seem to work towards bridging (at least some of) the apparent distance between a Levinasian responsibility toward the alterity of the Other who faces me and the political response demanded of critical disability theorizing. In our social work relationship with a disabled Other, our response is to that Other, even if it may be informed by the politics of the larger task, by the Other’s membership in this oppressed group. What is then required of us, may (or may not) be found to conform to or aid in the fulfillment of the broader goal and thus may not depend upon a totalizing enfolding of the Other in terms of the ‘same’ – *all* people with (intellectual) disabilities – that does violence to the Other (Rossiter, 2006). But,

like Rossiter's questioning of the will to knowledge in social work (2006), I wonder if this is really possible, or if 'being informed' inevitably negates a Levinasian response or respect for the singularity of the Other, negates the possibility of making this response to the Other into anything but an extension of my critical disability 'knowing'. Can I attend both to the individual and to the individual as a member of an oppressed group?

Perpich's reading of Levinas offers me guidance here as she writes that the Other does not demand that I fulfill her/his every need, or that I do exactly what I am told: the Other does not offer up a list of rules or principles that must be adhered to and which will constrain or guide what I do. The face opens up a discourse which then obligates me to further discourse, "to the practices of giving and weighing reasons and of doing so without taking my own "reason" to be the gold standard" (2008:149). This would appear to open a space for consideration of different knowledges (e.g., social work and critical disability theorizing) in working through to an ethical, a just response. Levinas himself writes that "(w)hen we talk about consciousness, we are talking about knowledge: to be conscious is to know; and in order to be just it is necessary to know: to objectify, compare, judge, form concepts, generalize, etc." (trans. Smith & Harshav, 1998:204). What is demanded by the Other is a personal response, and it is this that constitutes an ethical act (Perpich, 2008). It is in the I-Other relationship that the singularity of the face is enacted: "(s)ingularity is not what this relationship *recognizes*, but what it *produces*. Bernsaconi (2002), Perpich (2008), and Rossiter (2006) all understand Levinas' goal to be the re-thinking, the re-orientation of our thinking, towards ethics and that this is of no value at all unless it then comes to affect how we approach concrete situations and our relationships with Others. Our desire for justice for the Other must attend "both to the uniqueness of individual lives and to the ways in which those lives are embedded" within communities and within social categories such as

disability (Perpich, 2008:186).

Let me close with a return to the debates over naming. I vividly recall being part of a large (and somewhat heated) discussion over the politics of naming with the room fairly evenly divided along ‘disabled people’/’people first’ lines. The entire debate was singularly and immediately nullified by a young woman who took the floor to speak openly about the fluidity of her personal identification (as woman (of colour), mother, student, activist, disabled, impaired, etc.) with different aspects assuming prominence in different spaces, and at different stages, and requiring different strategies or choices depending upon the context. She refused to ever commit to a single identification. Levinas’ concern over the impossibility of representation can, I think, be similarly understood, and allow space to consider how, as social workers, to ethically respond to the Other in her/his alterity and as a member of an oppressed group. The face of the Other also refuses to be constrained by a single identification or representation. “I am *that*, it says, *but not only that*. I am, like every other, a unique and singular *who*” (Perpich, 2008).

Chapter 4 – Re-viewing Public Photographic Imagings and Imaginings of People with Intellectual Disabilities

Introduction

Let me here move the discussion into a re-view of the literature on public photographic representations of people with (intellectual) disabilities. My decision to do so at this juncture is predicated upon the domination of this literature by those writing from a critical disability perspective; hence this seems a logical progression. In addition, this re-view will inform the next section of this thesis in which I further contextualize the project through a discussion of Derrida's work on photography in his text, "*The Right of Inspection*".

Why Public Photographic Representations?

Photographs afford a means, a starting point, from which to explore how and what we come to know about others, how we see and respond (or not) to them, and how they might understand themselves. As social representations, photographic images are intricately bound up with knowledge and understanding of the self and the other in contemporary culture and, like language, provide a powerful means of defining individuals and social groups (Burgin, 1982; Garland Thomson, 2001; Newbury, 1996; Sekula, 1982). Permeating our environment in a vast array of institutional contexts, photographs serve a powerful function in the everyday, facilitating the formation, reflection, and the inflection of the taken-for-granted (Burgin, 1982). They are implicated both in shaping and in reflecting our ideas about others (Burgin, 1982; Harper, 2000). Public photographic images recapitulate cultural ideas about seeing the other, and, at the same time, they perpetuate those beliefs (Garland Thomson, 2001; Gilman, 1982). And, like all social representations, they teach us how to conceive the objects in it in a culturally determined and acceptable way (Garland Thomson, 2001; Sekula, 1982).

Burgin (1982:41) remarks upon the response - the “mood” or “feeling” - evoked/provoked by an image. He suggests that this response is dependent upon our “common knowledge of the typical representations of the prevailing social facts and values: that is to say on our own knowledge of the ways objects transmit and transform ideology, and the ways in which photographs in their turn transform these.” An image communicates by means of its association with some hidden or implicit text that carries that image into the domain of readability. For example, in the case of disability, prevailing ideology, social stigma, and memory contribute to the dialectic between the image and the text (Phillips, 2001). Yet, the cultural power of photographs is that the mediating effect of the image between the viewer and viewed is obscured, its operations are effaced. While organizing our perceptions of that which we ‘see’, they don’t let us know they are doing so. The social fact of photography often remains untouched (Burgin, 1982; Garland Thomson, 2001). This derives in part from a persistent and largely unquestioned acceptance of the indexicality, the truth value of the photograph, as an honest, authentic, transparent, and real representation; one capable of capturing the genuine subject and thus the most truthful and accurate mode of representation (Bal, 2004; Baer, 2002; Eco, 1982; Harper, 2000; Hart, 2004; Kratz, 2002; Newbury, 1996; Silverman, 1996; Tagg, 1993). This is intensified because the photograph typically (although digital manipulation complicates this idea) refers to an object that does (or once did) exist (Bal, 2004; Barthes, 1981; Garland Thomson, 2001). And it reveals the viewer’s ignorance, denial of, or lack of attention to the constructed nature of the photographic image, to the fact of its being a cultural production. Ignored is the understanding of photography, not as a window on the world, but as a place of work – a structured and structuring space within which the reader of the image deploys, and is simultaneously deployed by, the codes s/he is familiar with in order to make sense, to find the meaning of the photographic image (Burgin, 1982). Consequently, and as holds true for all attempts at social representation, the photograph is

capable only of showing us a ‘what’ and not a ‘who’ (Levinas, transl. Lingis, 1969). Further, in photography, “the image is often determined before it is made” (Starr, 2005:101). Nonetheless, as cultural images, photographs offer a measure by which to identify resistance to dominant social representations, shifting (and shiftable?) social attitudes towards marginalized populations, as well as an indication of particular sites of resistance to change (Darke, 1998). Here lies the heart of my interest in photographic images – their potential for both critique and transformation.

Photographically Imaging and Imagining Disability

The (in)visibility of disability.

I am compelled towards thinking about photography in the context of disability – or, more accurately, thinking about disability through the context of photography – because of the visibility of disability. Attending to the visualization of disability assumes a particular necessity because of the power of its cultural resonances (Garland Thomson, 2001). For individuals with impairments, self-identity, self-worth, and identification by others are situated in a broad field of representation – a field in which photography is powerfully implicated. Just as the photographic image is constructed, so too is ‘disability’ constructed or created and photography has played an important role in that construction (Darke, 1998; Evans, 1999; Gilman, 1982; Hevey, 1997).

And, like the invisibility of the constructedness of photography, so too is the construction of disability largely invisible. Photography is critically important to people with disabilities who are, most of all, conceptualized visually – in terms of the body (Darke, 1998; Garland Thomson, 2001, 2009; Newbury, 1996). And, because disability has been predominantly imaged and imagined in terms of the body, the starting point must be the body – a “refiguring of the disabled body” (Newbury, 1996:351). Jeffreys argues that “at the seam where body joins culture, every construction of the body begins and ends. On the efforts of culture to hide that seam, every

oppression depends” (2002:33). Constructed as the site of oppression, the body of the person with an impairment must also become the site of the struggle (Garland Thomson, 2001; Gilman, 1982; Newbury, 1996).

Photographic images set up an exchange between our public and private meanings of the body that proves a pervasive and powerful means of socialization. Even outside of photography’s influence on socialization, for most people, personal understanding, and our understanding of others, is to a great extent embedded in the social. Our “scenes of instruction”, those scenes that structure our entry (and that of others) into the language of identity are encountered in our relations and interactions with the social (Mauer, 2005:96). “(W)hat is determinative for each of us is not how we see or would like to see ourselves, but how we are perceived by the cultural gaze” (Silverman, 1996:19). For the person with a disability “the personal experience is over-determined by its social context” (Newbury, 1996:356-6). And by the power of the ableist gaze; practices of looking-at and staring that dehumanize and diminish people with disabilities (Garland Thomson, 2009; Ignani & Church, 2008; Davis, 2002). Sekula (1982) understands the public photographic image as an “utterance” (p.85) that carries with it a message. He suggests the majority of messages in public photographic images are spoken with a voice of authority – an anonymous authority – for which the only possible response is affirmation of that message and that authority. For people with disabilities, this voice of authority is perhaps not so anonymous. As regards the ‘look’ of the person labelled disabled, a possibly conflicted position thus derives from the authority of these message, from “cultural pressure to apprehend the world from a pre-assigned viewing position” (arguably an ableist position), and “psychic pressure to see it in ways that protect the [dis-abled?] ego” (Silverman, 1996:3). Consequently, the influence of media is undeniable. The public photographic image functions as a marker (and maker) of personal

identity (Newbury, 1996). It is the movement between apparently discontinuous practices, between the public and private spheres, that is the source of photography's power as an instrument of cultural expression. In addition, the photographic image possesses a significant affective potential, wavering “between (indexical) evidence and (pornographic, or traumatizing) affect” (Bal, 2004:2). Inherent within photographic work, however, is its potential as a vehicle for exploring and reconstructing understandings of disability, for de-centring re-presentations, in an educational as well as cultural context (Newbury, 1996). Photography offers a means, an opportunity, or the circumstance by which we might manage to ‘see’ productively or transformatively (Silverman, 1996) – to see disability differently.

What photographic images of disability exist and how are they framed, understood, and, as Hung asks, justified (2001)? While some authors claim that disability re-presentations abound (Darke, 1998, referencing film re-presentations, and Mitchell & Snyder, 2000, in their book on literary narratives), many others suggest that there are few photographic images of people with disabilities (Corker, 2001; Evans, 1999; Garland Thomson, 2001; Hevey, 1997; Marks, 1999). This absence is significant as photographic re-presentations have a powerful normative effect on social identity and create a repertoire of self-images to which people typically aspire (Mauer, 2005; Newbury, 1996). Understanding the photograph as ‘mirror’ (Silverman, 1996), for most of us innumerable embodied images exist, indicative of a range of social positions available for us to occupy (Chambon & Irving, 2003). There is, however, a paucity of photographic images available to people with disabilities (Phillips, 2001), and thus a limited number of poses available to people with disabilities – poses typically not of their choosing, but which they are taken into (Chambon & Irving, 2003; Wagner, 2000). Evans moves this further, suggesting that “status and authority in [photographic] images are implicitly linked with an absence of disability”

(1999:275).

If there are so few photographic images of disability, why then is this form of social representation so important? Hevey argues that although the structured absence, or erasure, of people with impairments and disabilities from photographic representations (their non-representation, or dis-representation) is near absolute, it is not total (1997). However, while it is true that photographic images exist, they are typically restricted to a single genre – that of disabling disability representations (or dysfunctional representations) – solidly embedded within the medical-model paradigm of disability that regards disability as an individual flaw and a personal tragedy, and evincing very clear and rigid markers of place and social position. Because of this, these are images that wound, that keep people with disabilities in their place (Kitchin, 2000). Encased within this genre, images are further restricted to a limited number of scripts/typologies; for example, charity advertising, ‘in-house’ health service magazines, medical or health educational journals and magazines (Evans, 1999; Hevey, 1997), or social documentary. Very rarely are images of people with disability considered as art, and even less often are such images made to be enjoyed for their own sake (Hung, 2001). Within each of these venues, the performative function of the photographic image of people with impairments is to show labelled people in very specific ways and for very specific purposes (e.g., as vulnerable and un-able and thus in need of benevolent care) and the production of the images is justified on this basis. Such photographs highlight only those aspects of the life of the labelled person that meet those ends (Atkinson & Walmsley, 1999) and constrain the reader’s engagement with the text. Very few alternative scenes are available.

Much of the writing on disability imagery adopts a taxonomical methodological approach to understanding this imagery (Darke, 1998; Millet, 2005) and suggests that images of people with

impairments typically rely on dominant stereotypes of disability, on objectifying taxonomies of deviance (Snyder & Mitchell, 2001). Such representational tropes of disability are rampant (Mitchell & Snyder, 2000). They include: the tragic but brave invalid/victim; the sinister cripple; the obsessive avenger; the ‘supercrip’ who has triumphed over tragedy; the comic misadventurer; animal; freak; monster; noble savage; object of pity; burden; punishment for one’s sins; devil incarnate; angel; messenger of god; the sweet innocent; or the eternal child’ (Corker, 2001; Evans, 1999; Hevey, 1997; Marks, 1999; Phillips, 2001; Sandahl & Auslander, 2005; Shakespeare, 2002). Within this image constellation, there is a prevalence of images in which disability is presented in either a medical context or as something which one ‘bravely’ overcomes in a struggle to be ‘normal’ (Darke, 1998). Speaking to the damage done by stereotypical imagings, Shakespeare (2002) cites “the power of images to define the experience of impairment, and to foster prejudicial attitudes towards disabled people” (p.164), and notes this historical distortion of disability discourses in images of people of with disabilities. The rhetorics of visual disability representations are at best understood as a mechanism of oppression (Garland Thomson, 2001). As articulated by Newbury, (1996), the connection between ‘disability’ and ‘the camera’ has often been a violent one.

As noted, one of the most critical features of disability photographic imagery is the tendency for viewers to perceive these images as ‘real’, as axiomatic, self-evident and/or archetypal truths about the human condition (Darke, 1998). To believe these ‘models’ of people with disabilities to be ‘real’ people with disabilities, “untampered with and authentically ‘real’ is to fall into the trap of thinking that we can have a direct experience of the truth and then find evidence for it in a photograph” (Evans, 1999:282). Nonetheless, the typical viewer of disability images, believes her/himself to be ‘seeing’ the truth, to being able to ‘see’ people with disabilities as they

truthfully are (Evans, 1999; Sontag, 1977), thus linking ‘seeing’ to ‘knowing’ (Harper, 2000; Tagg, 1988).

In fact it is the whole language of ‘seeing them’ which is the problem precisely because the oppression and inequality of disabled people is not caused by their bodily impairments but by the social arrangements which allow those impairments to become disabilities (Evans, 1999:285).

Photography is at the service of a particular kind of knowledge production and institutional function and, in the case of visual imagings of disability, photographic images and conventions are used in such a way as to guarantee what the reader of the images sees – disability – and that they see it in a particular way – as tragedy, as lack (Elks, 2005; Hevey, 1997; Garland Thomson, 2001). Speaking to the controversial photos of the Kallikak family taken by Goddard in the early 20th century, Elks (2005) theorizes that the audience sees only that which it is intended to see, that which serves to confirm what it already believes about disability. Goddard has been accused of retouching his photographs of people identified as ‘feeble-minded’, serving to exaggerate those features which ‘proved’ they were ‘retarded’. Elks argues that, in fact, the re-touching was unnecessary: “Even without the retouching, the photographs did not merely suggest feeble-mindedness, they *screamed* feeble-mindedness” (2005:278). Gilman, in his work with images of people labelled insane, argues that images of people with disabilities require few words as the images are understood to speak for themselves (1982). Troubling arguments as to the grounding effect of captions or text that accompanies an image (Phu, 2005), Gilman suggests that disability is so readily understood as to negate the need for explanation (1982).

The terms of admittance.

Hevey (1997:333) asks: “Under what terms are disabled people admitted into photographic representation?” Under what terms are these entrances rationalized? While (as noted) people

with disabilities are generally absent from photographic representations, they are sometimes included as a type of ‘presence’. In some cases, this presence is an ‘absent presence’: the character with the disability is physically or symbolically separated from the rest of society. In many other instances, this presence is as a representation that acts as a symbol of ‘otherness’ (Corker, 2001; Darke, 1998; Hevey, 1997; Marks, 1999; Sontag, 1977). Frequently, it is precisely this ‘otherness’ that is the rationalization for the image, and the image works to construct the disabled subject as ‘other’ to the extreme. Radically other, they are equally radically unknowable. Non-disabled viewers are not asked to identify with the person with a disability in the photograph – quite the opposite – what the viewer is asked to look at is really *other* (Sontag, 1977). The subtext is an ideology presenting humanness as distinct, different, detached from disability, if not from the body in general (Byrne, 2000; Linneman, 2001; Titchkosky, 2003). (This notion of the de-humanizing effect of photographic images is important and I will return to it anon.) Photographs depicting their “otherness” show people with impairments as being “placed within equations which have no engagement to them and which take their non-integration as a natural by-product of their impairment” (Hevey, 1997:333).

Evans (1999:275) references Roland Barthes (1973:155) and his ideas regarding “the way in which ideology in capitalist society ‘continuously transforms the products of history into essential types’ so that things lose the ‘memory that they were once made’”. The taken-for-grantedness of what we are given-to-be-seen (Silverman, 1996) is unquestioned. This argument parallels both Hevey’s analysis of the (ableist) social construction of people with disabilities as other through disabling images, and Hacking’s (1999) thesis on people-making, the social construction of ‘types’. In his attention to how we ‘make’ the world, Hacking (1999), considers how we organize the world into particular kinds or types, and then what that organization does to

us. He speaks to the construct of “interactive kinds” (p.130), a categorization that interacts with people and their behaviour and leads to a particular sorting of people, a sorting with particular consequences for how they are understood and what is done to them. He references child abuse as an interactive kind but his construct seems equally applicable to disability. This, for me, is because of his emphasis on the way interactive kinds differ from other kinds (e.g., natural kinds) – they have an evaluative component. Understood most often as a kind of deviance they are value-laden and serve to articulate the kinds of people one would desire to be (normal) or not to be (abnormal, impaired, disabled). In this way, these classifications impact upon how we are evaluated by others and how we evaluate ourselves. Hacking suggests also there are different responses to this categorization: passive acceptance or “rebellions of the sorted” (1999:131); in the case of the latter, the classification imposed from above is rearranged by those to whom it was supposed to apply.

In photographic images, people with disabilities are constructed as a particular ‘type’ of (objectified) subject and, as such, are uniquely vulnerable to a process of image specialization. In this way their image can be “constituted as a transaction in the public sphere: an image of a person who has Down’s Syndrome, for example, can be magnified a hundred times on a billboard – just because that person has Down’s Syndrome” (Evans, 1999:279). Not only is the image itself magnified, so, too, is the ‘otherness’ of the persons identified as disabled. As a transaction, particular consequences stem from this specialization and magnification. The circulation of popular photographic disability images calcifies the possible interpretations of disability that are embedded in those images (Garland Thomson, 2001). Further, the objectified ‘type’ evolves into a prototype; for example, Down syndrome becomes representative of all intellectual and developmental disabilities (Carlson, 2001). Garland Thomson, arguing that

disability is *not* an atypical occurrence, not the aberration we understand it to be, not unfamiliar, notes that the familiar experience of disability has been made strange and that photography, used as a representational medium and (as Evans (1999) suggests, a public transaction) has made it both more familiar and more strange (Garland Thomson, 2001).

The terms of disabled and non-disabled relations.

Social representations – including photographic representations – work to set up the terms of relations between different groups of people. In her essay on photographic representations of people with intellectual disabilities, Evans offers her “ideology-critique” of “the ways in which the production of meaning and cultural value serves to sustain relations of domination and subordination” (1999:275). She applies this critique to the tenacious belief in disability as being an essential characteristic as opposed to a socially created/constituted one – a belief that has been exploited to support ableist power-over people with disabilities. In the same vein, Garland Thomson, focusing on physical disability writes:

Disability is a representation, a cultural interpretation of physical transformation or configuration, and a comparison of bodies that structures social relations and institutions. Disability, then, is [...] not so much a property of bodies as a product of cultural rules about what bodies should be or do” (1997:6).

I connect these two critiques to Sekula’s (1982) refusal to separate the photograph from its representational task. Every photographic image is a sign of someone’s investment in sending a particular message to secure a particular task, leading Sekula to suggest that the task of cultural critique must be to understand a photograph’s meaning as related to its intention (1982). The majority of the literature on visual disability representations thus far would seem to regard the task of this particular cultural production to be the radical othering and subjugation of disabled people – one understood by both disabled subjects and non-disabled viewers. As a violent

technology of power (Allan, 1996; Bredberg, 1999), photographic images are able to socially construct people labelled disabled as subjects and objects of knowledge and power. This form of power applies itself to immediate everyday life which categorizes the individual, marks her/him by her/his own individuality, attaches her/him to her/his own identity, and imposes a law of truth on her/him which s/he must recognize and which others have to recognize in her/him (Foucault, 1982:212, in Allan, 1996:222). In this sense “disabled people are positioned to en flesh the theories of their oppressors” (Hevey, 1997:332).

This task of photographic representations of disability is revealed by the theoretical framework of ableist binary thought underlying these objectifying and stereotypic representations that serves to maintain a violent and devaluing divisiveness: us/them, able/disabled, human/non-human, desirable/undesirable, good/bad, mind/body, physically disabled/cognitively disabled, high functioning/low functioning (Carlson, 2001; Corker, 2001; Kittay, Schriempf, silvers, & Wendell, 2001). Yet Phillips (2001) notes that neither pity nor spectacle is a necessary component to disability imagery – they are a choice made by those soliciting and constructing the images. Stereotypic representations serve only to mark as different bodies with impairments. As arbiters of pathology, they reinforce negative attitudes about persons with impairments and perpetuate ignorance about the nature of disability. In that they become the central, confirmational images of disability, they are powerful icons, visible manifestations of disability (Elks, 2005). Such distorted discourses, however, neither accurately, nor fairly, reflect the lived experiences of labelled persons (Darke, 1998; Shakespeare, 2002), for they are positioned from ‘outside’ of these lived experiences. Disability imagery, like all photographic imagery, fails to reflect the life of the disabled subject within. As Garland Thomson writes: “this representational medium arrests time, freezes motion, and prunes away space which are the coordinates and the

context of “real life”” (2001:336). In presenting only a stereotypic version of ‘disability’, and ‘disabled person’, these images are not the stories of people with intellectual disabilities themselves – not about them – but only those of the more powerful non-disabled other. These then are images that are reflective of a destructive and self-enhancing ableist gaze that chooses to see disability in a very particular way; as tragedy and lack. There would seem to be an inadequacy between the portrait and the person (Chambon & Irving, 2003). Darke theorizes, however, that the point is not whether the stereotypes themselves are accurate in any literal sense (they are not), but that they do “reflect the realities of social interaction between the group that creates the stereotype and the stereotyped” (1998:188). “The pernicious stereotypes, lies, and false images can haunt a [disabled] body, stealing it away as surely as bullets do” (Clare, 2001:363).

So how does one understand this deliberate estrangement, this intentional distancing by non-disabled people from their disabled counterparts? For Evans (1999), one question to be asked when viewing re-presentations based on naturalist, or ‘real’, images (arguably the brunt of disability photography) is: Why should anyone believe in the reality of the image, and what does it do for them? “To believe in something being real is always also a psychological and emotional investment – there is always some trade-off for the viewer and a motivation at stake” (Evans, 1999:283; Hung, 2001). Hevey (1997) advances a psychological rationale for negative and disabling disability imagery positing that charity images of disabled people, for example, tap into a ‘normal’ psychological fear of bodily decay and death, of our existential awareness of always, ourselves, being-towards-disability. Presaging this fear of becoming disabled is adherence to the construct of ‘normalcy’ (Davis, 1995). “The question of what one sees – what one does see and what one is able to see – in encounters with the “visually extraordinary” reflects both the comfort

and the anxiety of considering oneself “normal” (Starr, 2005:97). Breckenridge and Volger (2001) hypothesize that confrontation with the figure with a disability calls into being the limits of concepts such as humanness and normality, and, as such, is intolerable. What is accomplished with stereotypic representations is the securing of the western emphasis on, what Britzman labels “exorbitant normality” (1988). Through the cultural imperialism of normative/able culture, the deviancy of disability remains tied to the possibility of normalcy (Carlson, 2001). By defining those with disabilities as fundamentally ‘other’, non-disabled culture sustains its valued identity as rational, good, in control, and knowing (Hevey, 1992; Marks, 1999) – as normal (Darke, 1998). Understanding people with disabilities as none of these things, this construction sustains the ongoing devaluation of those with disabilities. Darke (1998) questions why this genre of disabling disability representations has proven so resilient, despite the activities of disability activists and the emergence of a social model of disability. His own answer, echoing that of Evans (1999), is that it is the audience who demands and requires these types of representations. These are “the ones that are wanted”, the ones that work to confirm what it is that we wish to believe, that shut down unsettling questions about our knowledge and ourselves, and affirm, rather than change, the knower (Kratz, 2002:88).

Wounding exposures: De-humanizing the other / re-humanizing the Other.

In her essay on photography and the public sphere, Butler (J., 2004) addresses questions reminiscent of those of critical disability theorizing – questions about what faces are admitted into public representations, and also which voices are heard – who is (is not) counted as a viable actor, a viable speaking subject. She notes that:

To produce what will constitute the public sphere, however, it is necessary to control the way in which people see, how they hear, what they see. The constraints are not only on content...but on what “can” be heard, read, seen, felt,

and known. The public sphere is constituted in part by what can appear, and the regulation of the sphere of appearance is one way to establish what will count as reality, and what will not. It is also a way of establishing whose lives can be marked as lives, and whose deaths will count as deaths. Our capacity to feel and to apprehend hangs in the balance. But so, too, does the fate of the reality of certain lives and deaths..." (Butler, J., 2004:xx).

Many ideas relevant to this discussion are included in this quotation. First is the question of control over the production of public representations and their reception – over what appears but also over how it is received: “heard, read, seen, felt, and [as is important here] known” (Butler, J., 2004:xx). I have already spoken to this in terms of disability representations and their reception by non-disabled viewers. The question of the limits of the sayable, what can and cannot be said in photographic representation, and what, through the allocation of stigma, is rendered unsayable, I feel, has similarly been introduced. But at this juncture, I wish to attend to Butler’s notion of who is (not) counted as a viable actor, a viable speaking (or a silenced) subject; to the effects of all of these considerations on people with intellectual disabilities; and to a return to the question of responsibility.

The restricted public photographic imagings and imaginings of people with disabilities belie consideration of disabled people as viable subjects. Considering people with intellectual disabilities for a moment, this arguably is underpinned by their subjugation as knowers and rooted in cultural assumptions about ability, intelligence, personhood, and humanness (see, for example, Byrne (2001) for a discussion on intellectual disability, humanness, and personhood, and Linneman (2001) regarding mindedness and intelligence). Sontag (2003) notes that public photographic images created from the hegemonic perspective foster the illusion of consensus – the notion that all viewers will see it the same way. Such a view depends upon another, less illusory consensual belief: that people with intellectual disabilities are excluded from it. Re-considered from the lens of a critique of ableism, the rhetoric of the ‘hegemonic viewer’ lays

bare a number of assumptions at play in the processes of exclusion that bar people with intellectual disabilities from the production, viewing, and response to this type of social representation. Let me very briefly outline these here. The status of people with intellectual disabilities as depersonalized and dehumanized objects of knowledge, incapable of knowing, signals an elemental disbelief in their capacity for insight, memory, and reflexive personal and collective understandings (Baum, 1999; Fudge Schormans, 2005; Schaefer, 1999; Vakil, Shelef-Reshef, & Levy-Shiff, 1997; Vuletic & Ferrari, 2005; Wylie, 1984). Flowing from this (mis)conceptualization is the assumption that people with intellectual disabilities will not be sensitive to what is told about them in public photographic representations. What gets discounted, in a very general way, is the ability of people with intellectual disabilities to be aware of visual representations; to have the capacity to look at, think about or reflect upon them; to have an opinion, a political or moral judgement that they could and would choose to share with others (disabled or not) (Fudge Schormans & Chambon, 2010). These assumptions would appear to go some way towards explaining the lack of attention paid to seeking the perspectives of persons with intellectual disabilities and the noticeable lack of concern for the ways in which they, as individuals and as a group, may be wounded by these violent visual imagings and imaginings. For example, Susan Sontag writes of Diane Arbus' images of people with disabilities: "(h)er work shows people who are pathetic, pitiable, as well as repulsive, but it does not arouse any compassionate feelings" (Sontag, 1977:33). The subjects of the photographs don't know how "grotesque" they are (p.36).

Butler's essay looks at the dehumanization that occurs with certain representations or with a lack of public representations (both of which are relevant to people with disabilities), how these can lead to violence, and how we need to be aware of this (J., 2004). For oppressed groups, she

argues for the critical necessity of gaining representation (in particular, self-representation) for consideration as a viable subject, for being humanized. Failing to do so heightens the risk of being regarded and treated as less than human or not being regarded at all (2004). As noted, the dehumanization of people with (intellectual) disabilities is at the forefront of critical disability theorizing and is similarly important to this project. This is a dehumanization reflected in and effected by social representations, including visual imagings and imaginings. Butler identifies how the face in the public photographic image is often used in such a way as to deliberately effect a dehumanization (J., 2004). Interpreting media images using Butler's lens: through the production of the face of intellectual disability, framed in a particular way (relying on normative schemes of intelligibility) in the service of ableism, the face is so radically othered as to evacuate the human. The intent is to produce the paradigmatically human by showing exactly what it is not – intellectually disabled. The (paradigmatically) human is thus understood to reside outside the frame, beyond the image's borders. What the viewer sees inside the frame is the non-human or, in the best-case scenario in this scheme, the human face in its extremity. The face (of intellectual disability) then comes to represent that for which no identification is possible. It is this that is the condition for violence; this that accomplishes dehumanization in the Levinasian sense, and which moves Butler's discussion to include consideration of a Levinasian face, of a facing by the Other that obligates one to respond (J., 2004). The symbolic identification of the face of the other (with an intellectual disability) with the inhuman forecloses our apprehension of the human in the photographed scene. Failing to thus see the human, it is no longer possible to hear the call of the Other or to be commanded by the face. As Butler goes on to explain: "We cannot hear the face [of the Other] through the face [of the other] (J., 2004:145). The voice of the face that does humanize, that does point to the precariousness of life, that does demand our attention and response, has been masked (Butler, J., 2004).

Critical disability theorizing has, thus far, quite ably articulated the dehumanization of people with intellectual disabilities effected by public media images and other forms of social representation. And I think that, at heart, the task of such critical theorizing is, as Butler declares, “to return us to the human where we [non-disabled others] do not expect to find it, in its frailty^{xiii} and at the limits of its capacity to make sense” (J., 2004:151) in our normative schemes of intelligibility. To achieve this, Butler asserts the need to “interrogate the emergence and the vanishing of the human at the limits of what we can know, what we can hear, what we can see, what we can sense” (J., 2004:151). It is this that may then awaken us to the face of the Other, awaken us to the effects of what has been done to people with intellectual disabilities through visual imagings and imaginings, expose us to their wounding and thus to our own.

In that most disability imagery relies on objectifying stereotypes rooted in and determined to foster an ‘us’/‘them’ divisiveness and un-breachable separation, we know that the images wound. They further wound in the way they delimit how we know, what we do and don’t know about people with intellectual disabilities, what we tell others about them, and what we do with, for, and to them. They wound in that they affect how people with disabilities (often internalizing the ableism they experience in their daily lives) come to understand themselves, and how they experience their lives and their relations with the larger world. And they wound because the radical othering of people with disabilities that takes place in photographic images actively discourages non-disabled movement towards this other, attempts at respectful relationship or knowing. The public photograph itself provides non-disabled viewers with “an immediate yet distanced way to contemplate the disabled body without actually having to expose themselves to disabled people”, however this means that disability has “entered the public sphere as a highly mediated image shorn from interactions with actual people with disabilities” (Garland Thomson,

2001: 338). Placed alongside Garland Thomson's additional observation – that non-disabled viewers are under no obligation to respond to what they see (2001) – makes plain the link between Levinas and critical disability studies in the call for responsibility.

Public photographic images of people with intellectual disabilities are thus highly troublesome and require an ethical response; one that lets us attend more carefully to the effects of these images, to the precariousness of the life behind the image (Butler, J., 2004), to the signs of the pain (Phillips, 2001). What would appear to be required is a particular type of attentiveness – an attentiveness to the question of address. As it stands, the author/ity over the production and reading of visual imagings and imaginings rests with non-disabled others who, through the images, visually speak for, about, and over people with intellectual disabilities. There is no obligation to this other, to welcoming the voice of this other, hearing from this other what they see, hear, read, feel, and know. Quite the contrary: in reaction to (and reinforcing) the presumption of incompetence as regards people with intellectual disabilities the intended (assumed) viewer/addressee is the hegemonic non-disabled viewer. Nonetheless, given the power of visual representations to shape disabled people's perceptions of themselves, an intellectually disabled 'audience' must also be considered. It is thus necessary to shift the address, to turn it around somewhat. Hevey, writing about Arbus' work with people with disabilities and the responses of her non-disabled critics, notes that no one has asked the disabled "observed" what they felt about the images in which they figured: "Once again, the entire discourse has absented the voice of those at its centre – disabled people." (1997:335). Shakespeare (2002), Newbury (1996) and Millet (2005) argue that interpretations of disability imagery are far more complex than a limited focus on stereotypes might suggest, and call for a much broader debate on disability imagery. What would happen if the terms of the viewing

relation were flipped and people with intellectual disabilities were positioned to address their non-disabled other; sharing with them what they heard, read, saw, felt and came to know? What would they say about these images? There is an urgent need to do this as this piece is missing from our understanding of visual representations of disability. It is my sense that such a shift would allow us to take the effects of social representations more seriously. In coming to know more about the consequences of these images, about what it is that they do to people with intellectual disabilities, social work would better be poised to ethically respond.

Chapter 5 – The Right or Responsibility of Inspection

Introduction

It is to Jacques Derrida that I now turn my attention. My turn to Derrida is centred upon his work with a group of photographs by Marie-Françoise Plissart, in his text, *The Right of Inspection* (1998). I have chosen to work primarily with this one text, and not with his oeuvre more broadly, for it is the ideas expressed in this particular text that have most powerfully informed and anchor this work. Placed in conversation with Levinas' work on ethical responsibility, and with critical disability theorizing towards a re-thinking of disability, this text has very much shaped my research: the questions asked, the approach taken, and how I engaged the participants – the questions asked of them and the manner in which I asked them to engage in the work.

In particular, I am drawn to the way Derrida works with Plissart's images in this text; how he troubles that which we think we see, that which we think we know. Derrida's destabilizing passage through the image text is not analytical as much as it is an opening up of the text for innumerable (but not an infinite) number of possibilities (Derrida, 1998). It would therefore seem to build upon a critical disability reading of images by addressing the limitations of a critical reading – the rationalistic and analytic assumption that things are transparent or visible and can be seen, identified, taken apart, and fixed^{xiv} - while also continuing the Enlightenment project of a liberation from oppression with which critical theory is concerned (Smith, 2005), a concern that necessarily prioritizes the questions of rights. In this text, Derrida addresses the right of inspection over photographs – visual representations of another – and, in so doing, troubles the simplistic way we might approach our relationship to images (and, by extension, to the Other in the image). In that his trembling of our suppositions makes such certainties

uncertain and our knowledge suspect, the right of inspection suggests, too, the responsibility of inspection.

The Right of Inspection

In his text, Derrida questions our very “right to look”, this right being understood as a “right of inspection” – “one’s entitlement to look, to arrange or hold within one’s gaze, to take in a view, or to “take” a photograph” (1998:2). The asking of this broad question thus begins a journey of questions, one leading to another as Derrida teases apart what might be at play in the images, what it might mean, what questions are to be asked. I understand these questions to be highly relevant to the work I undertake with people with intellectual disabilities. Derrida wonders, for example, whether this viewing is the right of inspection or, rather, the invention of the other? (The invention of the other with an intellectual disability as de-humanized other, as tragic and/or fearsome freak, as lesser.) Is it the right of inspection, or the possession, the ‘taking’, of the other? (The consumption of the other, the enfolding of this other in my own terms (Derrida, 1998; Duncan, 2001)). Numerous subject positions are considered as he works with these questions: “Who has the right to watch the scene, to “capture” the images, to interpret them, frame them, and edit them? Who has the right to invoke narratives? And to be believed?” (Derrida, 1998:8). Is this the photographer’s right, that of the viewing subject, or of the photographed subject? Or, if one considers the photographic apparatus itself, does this right perhaps belong to the photograph?

While Derrida’s essay centres on who has this right with regards to visual representation, in particular, photographic images, I am also drawn to the question because of its link to social work, to social work’s history with “inspection”, in all its various forms and with all its various consequences. In social work, arguably this inspection can be understood to be, in the main, a

violent exercise albeit one couched in terms of benevolent expertise. (French Gilson & DePoy, 2002; Oliver & Sapey, 2006; Wenocur & Reisch, 1989).

Derrida addresses that which is said or unsaid, sayable or unsayable in photographic images, and the intertextuality involved in how and what we see. He is taken up by the question of the meanings we read in photographic images. When we view a photographic image we tell ourselves stories about that image – we ‘take’ a photograph. But whose story is being told? Is it that of the subject(s) of the photographs – her/his-story, their story? Of the photographer? The researcher(s) – my-story, our-story? Or that of the viewer(s) – her/his story, their story? Or is it all of these stories? And whose stories, and what stories, are not told, are forbidden? It is the emphasis on the meaning(s) gleaned, the ‘stories’ (not) told (to ourselves and to others) that results when we ‘look’, ‘take in’, and thus, ‘come to know’, photographic images of people (with intellectual disabilities) that is of interest here.

The photograph is an inscribed surface and what we see inscribed in the image influences our meaning-making. Campbell (1999) similarly understands the disabled body as an inscriptive surface; the inscriptions likewise influencing the meanings attached to bodies. Derrida’s is an interpretive approach and his emphasis in this work is on the undecidability of meaning. He challenges the idea that things may (exclusively) be one thing but not another – e.g., able or unable – and never both at the same time. Undecidability disrupts binary logic. The indeterminacy, the instability of meaning that is a central thesis in all of his work (Smith, 2005) here dismantles the photograph as absolute presentation or representation (Wolfreys, 2007). Opening up the photographs in “The Right of Inspection”, Derrida offers up the possibility of multiple interpretations, the possibility of new inscriptions, the possibility of disrupting the typical operations of the image. This is, I would argue, extremely important to the question of

disability imagery. His movement back and forth, in and out of different images, works, as Hobson suggests, to unsettle meanings, and by holding different meanings in relation to each other, to also proliferate meanings (1998). Interrupting and unsettling meanings can help us to sketch out the “not yet”, the “no longer” – it can allow us to reinscribe otherwise (Lather, 1989:8). It is not then a search to find the best disability representation, or the correct representation, but to, instead, broaden the debate about disability representations (Evans, 1999; Phillips, 2001), and thus open up new meanings of disability. In this way, Derrida would seem to regard photographic image texts as invitations: they “come to us with *invitations*; they invite us to see things otherwise and to then participate in effecting a transformation” (Smith, 2005:67).

For Derrida, there can be no single story: the meaning of any particular representation, of any single photograph, cannot and should not be fixed. He is opposed to the idea of frozen or fixed images, frozen or fixed meanings, and attempts to foreclose on meaning. He speaks instead of the impossibility of this fixity, of closure. The ambiguity and multiplicity of possible readings means there can never be a summation (Derrida, 1998). His work in this text thus connects to the re-view of the literature on disability imagery – a literature that reveals the attempts to restrict the viewer to the limits of a particular frame (Derrida, 1998), foreclose upon meaning, to limit the stories told. In that re-view, I spoke to the singularity of what is inscribed on the disabled body, and of what is inscribed in disability imagery, a restriction on meaning-making imposed through stereotypic representations that regard disability as tragic lack and which rely on a restrictive number of scripts that permit people with disabilities only a similarly restrictive number and type of pose. There are rules around disability inspection, rules around what you can see. As such, this re-view “exposes a history of the rights of inspection” (Derrida, 1998:8). Photographic representations thus necessarily entail a consideration of power. The conventions

of disability imaging orient the non-disabled viewer to very specific readings of the image and thus imaginings of disability. This “possession” of the photograph, of the photographed subject, “is negotiated through the right of inspection, and that right reverts to whoever possesses the camera; it reverts to the apparatus of capture held in someone’s hands” (Derrida, 1998:15). It is the “appropriation of a point of view....[that] unleashes violence” (p.15).

Wolfreys (2007) suggests that for Derrida, what matters is finding ways to disrupt received narratives, to interrupt and unfix what we (are directed to) think we know, what we think the image says. In “The Right of Inspection”, Derrida speaks to our desire for stories, our desire for the narrative order that stories can bring (1998). But this desire for order can be violent. Decisions around photographic representation and ways of reading these images thus risk violence: who appears, who disappears; what do we do with the other and with ourselves when we create an image, narrate a story, read an image? (Cixous, 1993; Derrida, 1998). The ideologies and power systems at play in the production of visual representations inevitably marginalize and exclude the other (DeShong, 2008; Smith, 2005): they exclude other texts, other possibilities or representation, other stories; and they exclude the Other (with a disability), both in the production of these texts and in the Levinasian sense of effacing the face. Derrida’s way of working is then an opening, and an openness towards the other/Other. This then is a doubling that takes place in his work – a double movement towards both the subject and towards the Other (Hobson, 1998). Derrida would seem, like many (most) critical disability theorists (and people with disabilities, and activists) to oppose (ableist) attempts to define, to fix, the meaning of something (disability) and to inscribe this in photographic representations in such a way as to limit the number of stories that are told, that can be told. For Derrida, thinking about the right of inspection then also addresses the opportunity to think about how one might exercise the right to

determine or at least to comment upon how one is represented (Derrida & Stiegler, 2002), and is thus then very relevant to the work at hand in this project. For these many reasons, the right of responsibility also entails a responsibility.

The Responsibility of Inspection

Derrida's work is then explicitly concerned not only with the right of inspection, but also with the responsibility of inspection – the responsibility to the other/Other that is inherent in taking up this right. Levinas' influence on Derrida is well documented (Llewelyn, 2002; Perpich, 2008; Smith, 2005) and recognized here. Smith argues that Derrida's work can be understood as way of engaging with the images, with photographic practices that is a response to an alterity which calls, summons or motivates it (2005). This is what transforms Derrida's project into a political one and also an ethical one. How can we keep open the spaces of meaning-making? Derrida's working with the images is a double-movement of dismantling – a productive dismantling intended towards a re-building towards something more just. It is an opening of the text to new possibilities, new understandings, new arrangements – to, as Lather (1989) articulated above, that which is to come or which could be – and to do so as a movement towards justice (Smith, 2005). Responsibility to the Other is tied into this recognition of the limits of texts, institutions, laws, and practices, recognition of what they are not yet but which they are called to be. It is this I find appealing given the fact that dominant social representations are a choice, they do not have to look like they do, they could be something else. For people with intellectual disabilities, justice has not yet arrived (Smith, 2005).

Derrida's way of working with a text as an opening, an openness to the other/Other; his understanding of the image as an invitation to see otherwise, to tell other stories; and as a summons or call from and for the other/Other lead me to thinking about the (im)possibility of

viewing photographic images of the Other as an extension of hospitality to the Other in the images. Smith argues that when undertaken as a means of breaking open and destabilizing accepted practices of social representation (of people with disabilities), Derrida's way of working with texts is hospitality and that, for Derrida, hospitality is justice (2005).

Elsewhere, Derrida himself writes that we have a duty to hospitality, an obligation to hospitality and to re-thinking hospitality in particular contexts (2001a). Derrida, for example, in *Cosmopolitanism and Forgiveness* (2001a), re-thinks hospitality in the context of the city: what the city could (not) be, should (not) be. My consideration of hospitality is in the space of social representation of disability – public photographic imagings and imaginings of disability, which up to this point in time might best be understood as “violations of hospitality” (Derrida, 2001a:16). Re-thinking how hospitality is (not) extended, and how it might be extended to effect an attentiveness, an openness, a more responsible response to the other of photographic imagery and the Other of the image. Social representations have a powerful effect on social relations – thus re-thinking these representations in terms of hospitality would seem critical. For Derrida, fulfilling our responsibility to the Other is complicated by “‘undecidability’; the condition for justice and ethical responsibility is precisely the dual state of *not knowing* what to do but at the same time being *obliged to decide*” (Smith, 2005). Nonetheless, Derrida stresses his understanding of hospitality both as a responsibility, a duty (ours), and as a right (of the Other) (2001a). What I think is required is that, in our reading of photographic images, in our telling of stories, we invite and welcome other stories; not only the stories we are given-to-be-seen, not only our own alternative stories, but those of Others – seeking out and welcoming these stories and taking them in. We must do this even if what these other stories reveal is unexpected, unanticipated, a surprise (Derrida, 2001b), even if we do not understand and they take us to the

limits of our own ability to read (Foti, 2006), even if, in upsetting the terms upon which we relate to others, they wound (Simon, 2001). We must take the stories in, and take the stories into account (Derrida, 2001b): listening, learning, asking questions, and telling. In this sense, it is ethical: “inasmuch as it is a manner of being there, the manner in which we relate to ourselves and to other, to others as our own or as foreigners, ethics is hospitality, (Derrida, 2001a:16-17). In that it orients us to the incalculable dignity of the Other, hospitality is ethics – it is the condition of the possibility of ethics (Smith, 2005).

Calling on Others

Pursuing Derrida’s ideas, the questions that my reading of *The Right of Inspection* has provoked, draws me also to the work of Roland Barthes (*Camera Lucida*, 1981), Walter Benjamin (*Illuminations, Essays and Reflections*, 1968), and Ulrich Baer (*Spectral Evidence, The Photography of Trauma*, 2002), work which both complements Derrida’s and poses different questions which are also compelling, also relevant. The work of these others can also be seen to touch upon important pieces in critical disability theory and in Levinas’ work on ethical responsibility. At this juncture, I will do little more than introduce these works and the main ideas that I am drawn to as these will be explicated in much greater detail throughout the rest of this thesis.

In *Camera Lucida*, Barthes addresses our affective relation with the images, how viewing of photographic images (in particular, those of people we know and care about) evokes an experience of self-in-relation to the image. What is, perhaps, Barthes most well-known construct – the punctum – articulates the manner in which the viewing of an image can disturb or wound the viewer and thus be a surprise (1981:27). For Barthes, the punctum is “a wound, a prick, a mark, a punctuation, a sting, a cut, a little hole”, an “accident which pricks me (but also bruises

me, is poignant to me)” (1981:27). Barthes goes on to suggest that to be wounded is a good thing: as a result he understands ““good” photos are those in which the object speaks and induces us to think, to reflect, to suggest a different meaning than the literal one”, although he acknowledges that such images may be regarded as dangerous and thus not preferred (1981:38). Barthes also speaks to the beyond of a photographic image, the promise of a future beyond a particular historical moment (the moment of the image’s production, the subject’s capture), and of the viewer’s desire to see beyond that which the image permits us to see (1981). It is this element of Barthes’ text that is most significant to my work.

I am drawn to Walter Benjamin’s articulation of the ethical imperative to disrupt the triumphalist perspective, as this is laid out in *Theses on the Philosophy of History*, in *Illuminations, Essays and Reflections* (1968). Thinking about this idea, through the question of the effects of written history of oppressed people constructed from the perspective (and for the purposes of) the victorious oppressor, Benjamin’s concern is with the violence of this historicity: not only with the violence revealed in the text, but also the violence effected by the text as it works to impose a singular meaning and to suppress the telling of other (different, conflicting, opposing) experiences. Like Derrida, Benjamin is concerned with who does and does not speak, whose stories are told, whose are not, and with the consequences of such. His call is to make possible the entrance of subjugated histories into our knowing. His project is thus a political engagement opposing oppression and, like Levinas and Derrida, it is further an ethical one as he is engaged, too, with the question and exercise of an ethical responsibility for the Other.

It is Ulrich Baer’s taking up of Benjamin’s thesis, his understanding of the triumphalist perspective and the ethical call to overturn it (in the fourth chapter of *Spectral Evidence, The Photography of Trauma*) that I take up most actively in this thesis. This text, entitled *Revision*,

Animation, Rescue: Colour Photographs from the Lodsz Ghetto and Darius Jablonski's Fotoamator, also links Barthes' notion of the beyond of the image to Benjamin's call for the interruption of the triumphalist perspective. Baer takes up these two ideas in his own work with photographic images of the Lodsz ghetto. He describes how the images have been constructed from the Nazi perspective and were intended to show the Jews in the ghetto in very specific ways, for very specific purposes. Consequently, he also foregrounds consideration of the stories that are told and not told; who is doing the telling (and why); and to whom these stories are addressed. Like the de-humanization of people with (intellectual) disabilities in public photographic imagery, Baer points to efforts by the Nazi photographer to de-humanize the subjects/objects of his images and to how this de-humanization authorizes different kinds of violence. Without making an explicit connection to Levinas, Baer's understanding of this de-humanization also seems to operate in the Levinasian sense – effacing what is most human about the face, and thus making impossible the hearing of the face of the Other within (an argument I have similarly begun about visual imaging and imaginings of people with disabilities in the preceding chapters). Calling upon Barthes, Baer argues that it is necessary to see the human beyond the image's frame in order to effect an overturn or rupture of the triumphalist perspective. In my work, I am choosing to expand this notion somewhat in an attempt to more explicitly incorporate a Levinasian responsibility to the alterity of Other and to address the documented de-humanization of people with (intellectual) disabilities in photographic imagery. Understanding the responsibility to see beyond that which the image permits us to see in this light, the emphasis is on seeing a human(izing) beyond.

For me, these three writers, like Derrida and like critical disability theorists, address the (im)possibility of images that de-humanize, of violent images that, in many different ways,

wound and are hard to bear. They concern themselves with the effects of the images and, understanding viewing to entail questions of address and response, with an ethical responsibility to the Other in the image.

Chapter 6 – Listening, Asking, Learning, & Telling

Introduction

In this chapter, I attend to two arguments made in the review of the literature on visual representations of people with intellectual disabilities. Speaking to the limits and potential violence inherent in all forms of representations, the first is the convincing assertion that these visual representations serve primarily to dys-functionally represent labelled people as a means of influencing what it is we (think) we know – and then go on to tell others – about them. Speaking to social work’s ethical responsibility towards the Other, the second is Hevey’s similarly strong admonishment that people with (intellectual) disabilities have yet to be asked their opinion of these representations (1997). How would people with intellectual disabilities interpret and respond to these representations and ways of knowing? How might they use this same medium, photography, to disrupt, destabilize, or problematize these disabling representations, knowings, and tellings? And use their own visual re-presentations to stimulate and demand other, more responsible, ways of knowing? These were the questions posed in and by my inquiry, and what I wish to do here is address how they were translated into a methodological approach to research – an approach strongly influence by the theoretical and conceptual frameworks outlined in the previous chapters – and to raise some of the ethical considerations and challenges involved.

Recognizing, Respecting, and Working with (understandable) Resistance

There is, by now, recognition that disabled people have had an ambivalent relationship to both research and the arts – “each has contributed to a disturbing tradition of normalization and exclusion” (Ignagni & Church, 2008:625). Such knowledge sits uncomfortably with the simultaneous demand for more meaningful inclusion of people with intellectual disabilities in research; calls for the ethical imperative of accessing these voices; and for self-representation.

How then to develop an approach that recognizes this discomfiture, that makes research more welcoming, and less something to be resisted by people with intellectual disabilities? One that begins, not with a (more typical) assumption of incompetence and inability, but with a (humanizing) presumption of competence; one that honours their perspectives, orientations, and strengths (as well as my own) (Thomas, 2001); is accessible; and demonstrates an openness to what they had to say and the different ways they might say it? An arts-informed approach seemed to lend itself to this inquiry with this population group for whom traditional research(er) insistence upon the written and spoken word can be both limiting and exclusionary.

The form of my research thus involved three movements. The first was to engage with people with intellectual disabilities in discussions about public photographic imagery of people so labelled, enabling them to look, stare, spend time with (Starr, 2005), and respond to these images. Here I gathered their thoughts, issues, questions, concerns, and reactions to these visual representations, to learn from them how they understood and felt about these visual constructions, and what they perceived to be the effects of such on their own lives. The second movement was the translation of their verbal responses into visual ones – creatively using photographic methods (i.e., the *Photoshop* computer software program) to transform original photographic images so as to reflect their critique and/or to put forth alternative re-presentations. The creation of new photographic images; the juxtaposition of original, new, and transformed images; the mixing of images and text, were also means by which they could visually respond to public photographic imagings and imaginings of intellectual disability, and visually realize alternatives. The third movement was to open, through exhibition, this work to different audiences, to other people with intellectual disabilities, and to non-disabled and differently disabled people with varying degrees of intimacy and experience with people with intellectual

disabilities. (Regrettably, the scope of the project, however, was extensive enough to necessitate I restrict the focus of this thesis to only the first two pieces of this work.)

My intent then, was to re-imagine how to engage with people with intellectual disabilities in research: how to “think creatively, to analyze artistically, and to represent imaginatively” (Thomas, 2001:273), not to arrive at a single fixed ‘correct’ meaning, but to point to the complexities of individual lives and collective experience. Following Cole and Knowles (2001), I hoped to advance social work understanding about the complex interactions between the individual lives of people with intellectual disabilities and the visual cultural context in which they live. I was equally concerned with the possibilities for the (ongoing) politicization of people with intellectual disabilities; using the project as a space for consciousness-raising by making available to participants the opportunity to comment upon, respond to, and engage with each other (and me) about, public photographic imaging.

In this chapter, I wish to shine a light on four dimensions of the approach that both engendered particular challenges and directed the writing of this thesis. The focus then is on people, representations, relationships, and mechanisms for change.

Extending an Invitation to the Participants

Who was invited?

The question of just who are the people who can take up this kind of work is an ethical one, requiring attentiveness to the importance of insider knowledge, and to redress for the historical (and contemporary) exclusion of people with intellectual disabilities from research that has very real consequences for their lives. My decision to invite (and include as actively as possible) people with intellectual disabilities derives from my concern to engage in “explicitly conscious

research” (Tregaskis & Goodley, 2005:366) that theorizes and challenges disablement; my opposition to inequalities effected by research contexts positioning researcher as ‘expert’ and people with intellectual disabilities mere objects of study; my belief in the necessity and right(ness) of involving people with intellectual disabilities in research; and an awareness that the involvement of labelled people strengthens the quality and relevance of research (Gilbert, 2004; Stalker, 1998). Tregaskis and Goodley (2005) point to the “ontological expertise” (p.367) of people with disabilities; how their experiences of living with disability and oppression, and of challenging these daily, should give them a privileged position in disability research.

Consequent to the social model of disability, there is strong support for including people with disabilities (beyond the level of participant) in research about them. For example, Charlton, 1998; Goodley & Moore, 2000; Hevey, 1992; Kitchin, 2000; Newbury, 1996; Rodgers, 1999; Stalker, 1998; Ward & Trigler, 2001; Zarb, 1992. We are seeing an increased number of participatory and co-researcher model studies that include people with disabilities (*other than* intellectual disabilities), as well as more and more research conducted by people with disabilities, although it is understood that disabled people are still not sufficiently included in mainstream research affecting their lives (Gilbert, 2004). Meaningful and active inclusion in research is a much newer (and less readily embraced) phenomenon for people with intellectual disabilities. This derives from common beliefs that intellectual disability poses particular challenges to participatory research that are perceived to be impossible to overcome. However, it is becoming clear that the challenge to inclusion is posed by the inadequacy of method rather than by the ‘inadequacy’ of the individual, and that “traditional frameworks fail when an ethic of participation is put in the foreground” (Gilbert, 2004: 299).

Challenging the doubters and naysayers, Goodley (1996), and Atkinson and Walmsley (1999)

engaged people with intellectual disabilities in life history and auto/biographical research. Booth and Booth (2003) used photovoice methodology to learn about experiences of mothering for women with intellectual disabilities. Based on qualitative interviews with people with intellectual disabilities about the impact of developing literacy skills, the book by Bennett, Jacoma, & Weinsten (1997) includes photographic portraits (directed by the authors) and essays written by the intellectually disabled participants. Ward and Trigler (2001) and Williams (2001) have turned to a participatory action model in research on self-advocacy. Others have used qualitative methods to explore subjective experiences of people with intellectual disabilities that fall under the rubric 'quality of life' (e.g., Alderson, 2001; Rapley, Keirnan, & Antaki, 1998). Such approaches link individual experience to public concerns and the development of social theory (Gilbert, 2004). Acknowledging my own indebtedness to these activities, my own work moves in a different direction, inviting people with intellectual disabilities to take up a different task, one concerned with existing public photographic (re)presentation.

Phillips writes: "when persons with disabilities create, circulate and own the image production processes, they define and control their meaning". These images have the potential to challenge and subvert the ways that people with disabilities are constructed and represented (2001:204). What is necessary is to put forward a disability consciousness that re-imagines existing paradigms (Hevey, 1997). Newbury thoughtfully articulates the purpose of including (physically) disabled people in a research project addressing photography and disability representations. Inclusion must move beyond tokenism. Nor can it exclude attention to questions of pain or oppression. It must be more than assisting disabled participants to achieve the selfhood denied them socially and culturally. Further, it is insufficient to regard this participation as 'therapy', providing inner fulfillment at the expense of social empowerment.

Participation must go beyond an individual pathology approach of self-fulfillment or therapeutic practice to facilitate development of a critical understanding of the social world and the ways people with disabilities are represented in it. Engagement is framed, not as personally rewarding, but as a means of taking part in public discussion and debates about disability and photography in the social and cultural realm and using photography as a vehicle for the integration of different and multiple levels of understanding (1996). It engages with and locates individuals with disabilities as (able) “articulators” and “interpreters” of experience (Knowles & Thomas, 2002:124), affording a means of breaking out of allocated spaces (Kuppers, 2003).

My decision to invite people with intellectual disabilities to join in this project is then empirically, philosophically, and ethically driven: an emerging literature; my own assumptions about disability and people with intellectual disabilities; knowledge of the power of visual representations; and my disquietude over how we have come (could/should come) to know intellectual disability and labelled persons, obligates me towards this invitation.

Who accepted the invitation?

Like the work done by Booth and Booth (2003:431), this project is both recognition and articulation of the importance of engaging with people with intellectual disabilities in alternative, subversive, and transformative ways that trouble and move beyond “the barriers to communication and participation erected by...the ‘normative methodology’ contained in standard text books.” To do this necessitated their positioning as experts, as the ones with the right and ability to do this work. To find, and invite, these experts, I approached a small number of relevant service agencies and met with a similarly small number of labelled persons to explain the nature of the research, and the tasks at hand.

I explained how the task was not a series of individual interviews with people with intellectual disabilities positioned as respondent. The project was concerned instead to have people with intellectual disabilities work individually with disability imagery, as well as with each other and with me; to be the expression of individual voices but also of a group voice (granting recognition to their uniqueness but also of their shared membership in an oppressed group). The intensity of the task could not be ignored. My intent was that they engage with the images at length, and that they delve as deeply as was comfortable for them into the images, their responses to them, and the effects on their lives. Consequently, it necessitated working with a very small group of people (four). What were readily apparent were the more practical considerations of communication and cognitive issues with people with intellectual disabilities as they potentially impacted upon the relational aspect of the work. It was not necessary that participants be able to speak, but that each of them be able, in some reliable way, to articulate and express their thoughts about the images and engage in ‘conversations’ about them. One participant did have some communication difficulties; another had a beautifully poetic albeit individualized way of using spoken language, however, with patience and familiarity, we were quickly able to understand what was being said.

The research group members did not have to know each other beforehand but, as it turned out, three of them did as they were supported by the same community living service agency and belonged to the same self-advocacy group. They had known each other and worked together in this capacity for many years. The fourth person to take up the invitation, the youngest, was in the throes of transitioning from child welfare to the adult community living sector – while not part of any self-advocacy group, many years in care offered untold opportunities to learn self-advocacy. What the four participants regrettably shared were common, and frequent,

experiences of marginalization and oppression. Sharing what *they* deemed important for the reader to know, let me introduce them to you here:

Bob lives in his own apartment (he has a social worker who helps him out from time to time). He is especially proud of his job – maintenance work at a local community recreation centre. When the supervisor is away, Bob is the one asked to ‘be in charge’. A quiet, gentle man, in his early 50’s, Bob is very close to his father and brother, both of whom he visits weekly. He has a strong faith in God which he says has helped him often through difficult times. Bob is a member of a self-advocacy group and was very excited to participate in a research project.

Sam, a young man in his early 20’s, is very active in the self-advocacy movement. He currently lives with his family and works part-time at a fast-food restaurant. He enjoys his work at the restaurant but reports he has, in the past, had a number of less successful jobs. But it is his involvement in numerous social and self-advocacy organizations that most informs his sense of self and from which he derives the most pleasure. Sam volunteered to be the research group secretary: being responsible primarily to remind us all of meeting dates, times, and locations, and to keep our meetings within the prescribed time. Sam’s calendar is always full (which made scheduling research meetings a ‘nightmare’) and this is how he likes it.

Robin is also in his early 20’s and this is a time of much change (and some uncertainty) for him. He has recently moved into a supported apartment program (which he really likes) and is working at a grocery store for a few hours each day. His job is very important to him and he considers himself a very responsible employee. He is planning to attend college and views his participation in the research project as a means by which to improve his chances for admission. Music, clothes, friends, and cars (the sportier and faster the better) are a major part of his life.

Donna joined the research project because she understood it as a means of letting non-disabled people know what it is like to live with an intellectual disability, to live with the way people treat you. Like Bob, she is in her 50's and is active in the self-advocacy movement. She, too, lives in her own apartment and, while desiring of a job (she very much dislikes being poor), she often gets upset at how people treat her and this can get in the way of keeping one. Donna also likes to be part of things and she is involved in many social activities and groups. Donna is quite proud not to have missed a single research meeting.

What is important to state up front is that they all *insisted* upon using their own names in this work (and in any presentations or papers that come from the project). And while I took great pains around issues of informed consent (see appendix A) and explaining possible risks, my arguments were countered by their desire to claim the work as their own. Sinding, Gray, and Niskar note both sides of the debate around confidentiality (2008). On the one hand is this desire to claim one's work, one's experience. On the other hand, there is risk involved in being identified in research – especially research that may have a larger public audience. People's lives and stories may be misrepresented, and/or become publically visible in potentially lasting ways (2008). For people with intellectual disabilities, there is the risk of even heightened surveillance (Booth & Booth, 2003). Nonetheless, Sam, Bob, Robin, and Donna chose to be more visible, to use their own names. Each arrived at this decision at a different point in the research process: for Donna, it was very early on. Sam and Bob came to the decision a little more slowly. All three opted for even more publicity by making the decision to use their own images in the work. Their decisions were politically motivated – this is *their* work and they want people to know that. Robin was the last to come to the decision to use his own name and his

publicity was restricted only to the use of his name – he refused to use his image and, as the reader will come to learn, his attempts to secure visual privacy were far-reaching.

Did they know what they were getting in to? Did I?

What I worried over from the outset was that I was inviting the participants to take part in what might (would surely?) prove to be difficult work. I could not predict how they might respond to the images but I knew many of the images disturbed me. It was my sense they, too, might struggle with the images and the implications of these images. I understood, too, the vulnerability inherent in the creative process – vulnerability linked to mine, Sam’s, Bob’s, Robin’s, and Donna’s relationship with the topic (Sinding, et al., 2008). As these authors suggest, the intense collective search for images and language to convey experience calls for something more, and for something different, than what is typically required in research: “anxiety and distress are inevitable”, nor does making an informed choice “foreclose distress” (p.461). Much attention was paid to their possible vulnerability, but I wish to make clear this was not because of a (paternalistic, maternalistic, diminishing) belief in the inevitable frailty or inability of labelled people to manage tension, upset, or difficult things – a vulnerability too often assumed inherent in and specific to intellectual disability. Certainly, many people with intellectual disabilities experience sometimes very difficult lives, and my own experience had long ago taught me never to underestimate the capacities and abilities of people with intellectual disabilities. It was, rather, my awareness of a potential vulnerability wrought by the difficulty of the images themselves, the intensity and personal nature of the task, and the extent to which I was asking them to immerse themselves in these difficult image and issues.

So, what happened? The group members did, indeed, experience many instances of upset – sadness, anger, confusion, resentment – and distress in their work with these sometimes

wounding images. Their emotionality was both testament and critically important to understanding the effects of these images on the participants, and to the integrity and effectiveness of what they produced – their visual responses (Sinding, et al., 2008). However, group members were not overcome by, or locked-into, this distress – they and I were able to manage it. My many years of personal and social work practice experience with people with intellectual disabilities, and my developing relationships with the group members – and theirs with each other – were drawn upon to help contain and safely and sensitively attend to this. The project came to be regarded by Donna, Bob, Sam, and Robin, as a space(s) for the safe expression and voicing of this emotionality. The creative process itself offered a way to respond to distress as it emerged (Sinding, et. al., 2008), and group meetings functioned as another safe outlet^{xv}. I am not denying or minimizing the emotional struggles the group members underwent, for “these struggles matter in ethical terms” (Sinding, et al., 2008:461), but the research experience was not singularly one of distress. Robin, Bob, Donna, and Sam experienced many different emotions as a result of their involvement in the work: humour was a notable element in our meetings; a caring and closeness developed between the group members and myself; visible (and felt) shifts in their understandings of their own abilities; and recognition from others of those abilities translated into pride in their accomplishments, and a different sense of self. As Sinding et al., write: “the benefit of the production was not separate from the distress; indeed, it was in a certain sense embedded in it” (2008:464).

Choosing the Objects for Looking

A second dimension of the approach concerns the careful selection of photographic representations for use in the project. The participants were being asked to respond to particular images but also to respond to the larger idea of being visually represented, and to being visually

represented according to the rules of public disability imagery. Guided by the research literature, an array of images were drawn from newspapers, charity advertising, service agencies, medical journals and magazines, social documentary, and (more rarely) photographic art – the most typical types of photographic images of disability (Evans 1999; Garland Thomson 2001; Hevey 1997). As was noted in the literature review, there is a paucity of public photographic images of intellectual disability and this was a limiting factor. There was an element of arbitrariness to my selection: drawing from these sources I selected images that seemed, to me, representative of the disability imagery spoken to in the literature, but also those in which I could detect a certain ambiguity and/or which appeared to point to the challenges of representation.

In total, I selected sixteen images – also an arbitrary number – but my concern was not to overwhelm the participants. To each meeting, I would bring 4-5 images. From these, Sam, Donna, Bob, and Robin would select which image(s) to work with that day. At times, some of them brought in personal photographs and these would sometimes come into play with the image they selected from my offering. Almost exclusively, the research group members chose to cooperatively select a single image to work with as a group. (There was only one exception and this will be addressed in subsequent chapters.) Having decided upon an image, I would engage them in a discussion following a series of questions I had developed, based upon my reading of the literature on photographic representations of intellectual disability and rooted in the theoretical and conceptual frames of this project (see Appendix B). In this regard, the project was reminiscent of photo-elicitation (Harper, 1998; Prosser & Schwartz, 1998). There was no imperative to follow this research guide to the letter, only that we (eventually) address each question for each image. Typically, conversations moved in, out, and between these questions, often re-visiting one question in response to a point or idea raised by another. As the group

members became familiar with the questions, they themselves would move the conversations to the different ideas being posed by the questions and my task, prior to the close of each meeting, was simply to ensure they had covered them all.

Sharing Conversations

Concerned to advance an agenda for inclusive disability research (Tregaskis & Goodley, 2005), my structuring of the researcher/researched relationships was guided by a philosophically and ethically-based commitment to cognizance of and efforts to level out (or reduce the gap as much as possible) the power imbalance inherent in this relationship (Gilbert, 2004). It was, simultaneously, an attempt “to challenge at both theoretical and practical levels the commonsense assumption of a binary opposition that separates disabled and non-disabled people...and which thereby fails to recognize the relational nature of disablement, empowerment and interdependence in research and in life” (Tregaskis & Goodley, 2005:365). Positioning Donna, Bob, Robin, and Sam as the ones who know, and myself as the one who wants to learn – and giving voice to this – acknowledged my dependence upon them. (As we became more familiar to each other, and to develop a mutually caring relationship, Donna, Bob, Sam, and Robin came to regard themselves as essential to my ‘passing my Ph.D.’, to ‘worry’ over me in the way friends will, and to also take a measure of pride in being able to help me with this task.) At other times in the research, we worked in ways that benefitted them: exploring together avenues for support around issues important to their lives - existing issues that were drawn into the research (for example, pending changes to the disability support mechanisms they relied upon prompted a letter writing campaign within the group). Atkinson (2005) reports that this interdependence, and the need to engage in activities that fall outside a more typical, and more restricted, research relationship are not uncommon in projects involving people with intellectual

disabilities.

What suggests to me I was even partially successful in reducing the gap can best be demonstrated by an example. Early in the project we were invited to present our work with three images at a conference. Preparing for this conference, Sam named the project the “What’s Wrong with this Picture?” project. In addition, the four members made the decision to designate themselves a ‘research group’ (one which also included me) and to call themselves the *PhotoChangers*. This gesture inaugurated a transition in how the work was viewed – ‘Ann’s research’ evolved into ‘our work’.

The work proceeded, not as interviews, but as conversations: the group members’ individual and collective conversations with the images – with individual images and putting images in conversation with each other – and their conversations with each other, and with me. What proved to be important was the manner in which I asked them questions. This was informed by literature pointing to potential challenges to gathering information from people with intellectual disabilities (see for example, Atkinson, & Walmsley, 1999; Booth & Booth, 1996; Goodley, 1996; Rodgers, 1999; Stalker, 1998). But, it was equally about approaching them with an openness and an attentiveness to what they had to say, and to their saying of (often very difficult) experience; a being-with intended to convey my valuing of them, their knowledge, and experience. I entered the conversations with patience, persistence, and a gentle (and easily terminated if the task became too uncomfortable) encouragement to really move into the image, to delve into their reactions to them and the reasons for such. Like Solomon’s careful and careful listening (2007), I listened, learned, and asked more questions - often feeding back to them what they had said in my efforts to ‘make sure I got it right’ (Rodgers, 1999). This was reciprocated as they responded to me with an openness of their own, with the demonstration of

their own patience with me, and persistence in ensuring that I *did* understand.

Another notable transition occurred as the group members not only engaged in these conversations, but how, more and more, they directed them in a number of ways. At the beginning of each meeting, Robin, Bob, Donna, and Sam selected the image to be worked on and, as a group we all articulated the meeting's agenda. They retained control over which questions to (not) answer, and what to ask each other. Some questions were (variably) embraced, some (variably) resisted, others were not understood and had to be abandoned (e.g., a question, "did they see anything 'hiding' in the image?" proved confusing). In contrast to more typical research relationships, they would often ask questions of me, effectively 'returning the gaze' (Gallagher, 2008:73). In addition, they quickly changed the structure I had planned for working with the images. Whereas I had envisioned discussing one image at a time and, once finished, moving on to the next, the group members made clear their preference: while each meeting would commence with a single image as its focus, they would call into play other images, moving back and forth between images, conversations, and ideas in any given meeting. They quietly, but insistently, pushed back if I attempted to move to another image or idea before the group members felt the current one had been exhausted; an outcome unveiling not only the depth of their engagement, but the need to allow for enough time for the work.

Inevitably memories of personal experiences were evoked and found their way into these conversations. Made plain was the interconnectedness of their lives with the images: what the images (mis)represented about their lives; what in their lives was reflected in the images (e.g., disabling relations between disabled and non-disabled people (Darke, 1998)); what in their lives was *not* reflected in the images (e.g., lives lived with purpose and pleasure); and the effects of these types of images on their lives. Pointing to the interpretive nature of the group members

work with the images, these conversations were then a means of coming to a deeper meaning-making (theirs and mine) that reflected the interconnectedness of the images, the thoughts and feelings they provoked, and lives lived with an intellectual disability and societal responses to it.

Mechanisms of Change

This dimension of the project expands upon the notion of ‘response’. It was about giving the *PhotoChangers* the opportunity to do just that – the opportunity to visually respond to what they saw in the original images by transforming them: the opportunity create something that might work (in conjunction with? more powerfully than?) their spoken response to disrupt that which is (thought to be) known about intellectual disability and our relationships with people with intellectual disabilities. My own epistemological and ontological assumptions about intellectual disabilities and people so labelled, and my commitment to accessibility and inclusion, shaped how the arts were drawn into this inquiry (Ignagni & Church, 2008). Created was a space and means by which Sam, Donna, Robin, and Bob might resignify intellectual disability and its cultural reception; might intervene in the repertoire of disability representations to destabilize our understandings (Snyder, 2005). Cole and McIntyre (2004) proffer that the researcher must be committed to rendering the emotional component and the complexities of the subject in forms that are capable of activating the senses. The project was an opportunity for the group members to creatively and visually express their critique and their emotional responses to the original images.

The activity undertaken here is reminiscent of, but deviates from, photovoice methodology. Like photovoice, the research process used in this project puts people with intellectual disabilities in charge of directing the camera’s gaze; of representing themselves and depicting their own situations. Privileging the perspectives of historically silenced and marginalized voices, it

challenges the accepted politics of representation by shifting control over representations from the more powerful (non-disabled) to the less powerful (intellectually disabled person) (Booth & Booth, 2003; Castelden, Garvin, & Huu-ay-aht First Nation, 2008; Ignagni & Church, 2008). As Burgin (1982) notes, all photography is a function of point-of-view – photovoice shifts that point-of-view from, in this case, the non-disabled observer to the disabled observed (Booth & Booth, 2003). My approach, however, can be distinguished from more typical uses of photovoice by its connection to arts-informed research. In its most common form, photovoice entails giving people cameras; asking them to take photographs that speak to a particular topic, experience, or research question; and then engaging with them in discussion of the photographs taken (Frohmann, 2005; Molloy, 2007; Radley, Hodgetts, & Cullen, 2005). The task in this project was not simply about having participants take their own photographs as a means of conveying experience and re-presenting self. Nor is it restricted to looking at past and possible representations (although this was certainly an element of the task). In fact, the group members did not take any photographs themselves. It is, instead, concerned with broadening the debate on photographic representation (Hevey, 1992; Millet, 2005), and broadening the epistemic terrain of knowledge production (Ignagni & Church, 2008). It is about working through and with photographic form to ask questions, to generate and gather information, to theorize, and to then communicate what is learned (Ignagni & Church, 2008); with using photography as a means of investigating disability (Hevey, 1997; Newbury, 1996; Phillips, 2001). The project's emphasis on the group members' creative production of new image-texts is both embedded in and disruptive of the original photographic representations.

The *PhotoChangers* did direct the taking of some new photographs that spoke to their situations, images that were intended to make visible their opinions and feelings, however (as I will soon

explain) this was done a little differently than is typically the case in projects using photovoice. It was, however, the transformation of existing public photographic images that took precedence and distinguishes this project from more common uses of photovoice. These transformations were opportunities to re-image and thus re-imagine ‘intellectual disability’, disabled and non-disabled relations, and the production, delivery and reception of disability imagery. As articulated by Ignagni and Church, they were a means by which “to control the words, images, and ideas that have historically worked against them” (2008:627). This was not just about giving voice, although the importance of this for Donna, Bob, Sam, and Robin cannot be underestimated. It was very much about politicizing disability; the giving of a critical and political account by a group of disabled people – one that challenges the preponderance of one-dimensional representations and understandings of intellectual disability, and which attends to living with and through ‘disability’ as an everyday experience (Ignagni & Church, 2008). The task was not to reach the right or correct re-presentation – an impossible task – but to point to the challenges, and consequences of, representation of the other (Butler, J., 2004; Newbury 1996; Phu 2005, Shakespeare 2002).

For the transformations piece, Ted Myerscough (a digital media consultant) joined some of our meetings. (Ted did not attend all our meetings, only those specific to transforming images or creating new images, and those focused on preparing for conference or other presentations.) Bob, Donna, Robin, and Sam would tell Ted their thoughts and feelings about the original images and how they wanted to either change the original or take a new image instead as a route to visually realizing these ideas. Attending very carefully to their ideas, Ted would creatively use *Photoshop* to try to visually articulate the group members’ ideas, and/or take new photographs which the group directed. He would present his re-working of the originals, or his

new photographs, to the group members and me and we would all work together until the group was satisfied with the result. The group members would then direct Ted and I as to how these images ought to be arranged for viewing: some singly, others paired or juxtaposed, some used more than once, some with text and some without. In every instance, the group members had the final say. “What is offered is a critical, alternative perspective, not necessarily singular, but definitely within the control of those who have been subject to demeaning and diminishing gazes” (Ignagni & Church, 2008:631).

DeFreitas (2008), and Sinding et al., (2008) speak to the impact of art in coming to know the Other. Ignagni and Church (2008) proffer that this infusion of arts-informed methodologies gives greater authenticity to the work than disability studies approaches typically afford. It is a way of furthering praxis and affording disabled people alternative ways of being seen and heard, ways that destabilize and trouble embedded and unquestioned knowledges and relations between disabled and non-disabled people. It challenges, too, the inhospitability of academia to inclusion of people with intellectual disabilities in knowledge production (Goodley & Moore, 2000). In this project, the group’s work attends not only to how they see themselves, but very much to how non-disabled others see them. The imagery they created results in new, alternative, and multiple meanings – a Derridean proliferation of meaning – and new avenues for encountering people with intellectual disabilities that require the viewer to relate very differently to them, to relate in ways not typically available in everyday life (Ignagni & Church, 2008).

Careful and Care-ful Looking and Learning

Holding all of what had been done, I then entered into a solitary space of working to interpret and make meaning of all the written, spoken, and created pieces. I pored over my extensive journal notes, notes in which I recorded key ideas stated; questions I had but which I chose not to

ask, or wrote down in order to pursue later; things I observed about the individual members, about the relational dynamics; and connections and musings over things they shared with me outside of meetings (for we often travelled to and from meetings together). I worked, too, with the videotapes of each meeting – videotapes made to address concerns around communication issues; to enable me to re-view and better understand non-spoken communications and interactions; and to free me from intrusive and less-respectful note-taking during meetings. Repeatedly watching these tapes, paying attention not only to what was said and how it was said, to how they looked (or did not look) at the images, but also to Donna's, Bob's, Robin's, and Sam's physical, emotional, individual, and collective reactions, I was enabled to attend to dialogic and non-dialogic discourses (Thomas, 2001), to the embodied experiences of the work (Richardson, 2001) – cognition and affect – and also to the 'being lived' experiences and encounters taking place in the space and time of the research. I tried to keep both the complexity of what each individual group member said and also the commonalities and divergences. Understanding that Bob, Donna, Robin, Sam, and I, as disabled and non-disabled persons likely each had different experiences and expectations of the research (Tregaskis & Goodley, 2005), I was careful, too, to attend to 'me', to my own attending. Not ignoring the ways in which my asking questions, my responses, my (in)attention may have influenced their response, I acknowledged and made visible my own presence in the work (Cole & Knowles, 2001), an inclusion of the self that is an epistemological statement about the connected nature of knowing, and a political statement about the non-innocence of the researcher (deFreitas, 2008). I created lengthy transcriptions of each meeting that incorporated all of these elements. And I engaged with the group members' transformations, their new images, their juxtaposition of different images with each other. Very much an iterative process, my engagement with the work entailed attending to individual and groupings of pieces, circling back and circling through, visiting and

re-visiting their encounters, conversations and all of these materials.

It was, thus, a “humanly situated” interpretive effort, filtered through my own, and the group members’ eyes and perceptions (Richardson, 2001:250) to uncover, illuminate, and also to construct “the fabric of new meanings” (Thomas, 2001:276). As such, it bears the limitations, as well as the strengths, of human feelings, activity, beliefs and understandings (Richardson, 2001:250). Sinding, Gray and Niskar speak to the ethically relevant outcome of this type of process in arts-informed research: the researcher is better able to appreciate the situation of the Other (2008).

Accountable to a Re-counting

From their work on “ethical issues and issues of ethics” in arts-informed research, Sinding, Gray, and Niskar speak to the potential of alternative means of representing research ‘results’: “There is it seems, something about the process of representing things artistically – of undoing the familiar language, of reaching for new words, of distilling the experience into an image, of embodying it – that is especially powerful, is especially disruptive” (2008: 460). There was little doubt in my mind as to the power of Sam’s, Bob’s, Robin’s, and Donna’s work. What I felt most heavily was the responsibility of re-presenting this work in a way that was just, and which did justice to the depth and strength of it. As Derrida writes, “there never is any writing without responsibility, without an other to whom it must respond” (2001b:8). How then to textualize what happened in the project, to transform these lived encounters into the written word? How to convey the multidimensionalities of the voices and experiences, and how to include “not only the dialectic of thought but also the essence of feelings expressed and emotions evoked” (Thomas, 2001:275)? How to demonstrate, in my writing of the thesis text, the group member’s deeply grounded and personally felt understandings and perspectives (Richardson, 2001)? How to make

plain my own position, my contribution or influence – my fingerprint – and also the intersectionality of our work together; how to situate myself in the telling of the research (Booth & Booth, 1996; deFreitas, 2008)? I was concerned with holding myself accountable to an ‘honest’ and respectful re-counting or re-presentation of the group members’ work, to an honest knowing and telling, to the extent this is even possible (Cole & Knowles, 2001; Richardson, 2001).

The next section of this thesis is titled “*What’s Wrong with this Picture*”. Included are six chapters. The first, as outlined in the introduction, is a presentation of the eleven original images the research group members chose to work with and some contextualizing information. The last, a photo-gallery of these originals, their transformations, and the new images created. These two chapters enclose the four others that are my articulation of the work undertaken and completed by Sam, Donna, Robin, and Bob. In writing these four chapters, I took my lead from Thomas, with the result being a layering of transcribed voices, narrative, and text, and then the interweaving through all of this of the visual images the group members worked with – the originals, the transformations, and the new images (2001).

The chapters are structured thematically – a single theme per chapter. My reasoning is rooted in recognition of the manner in which the *PhotoChangers* worked with the images. As I noted, the group members did not work with the images one at a time, instead they put (and kept) them in conversation with each other. What thus emerged was not a discrete conversation for each of the eleven images, but four particularly insistent thematic ideas encapsulating all eleven. These multiple, intricately connected ideas speak to the strength and complexity of the group members’ work with the images. The chapters are further organized biographically. Fronting the group members’ personal signatures in the work revealed the primacy of each theme for one group

member. For example, while all four participants were concerned with, and affected by, questions of care, this notion took on a particular urgency for Bob. So, too, did contradictory perceptions of power consume Sam just that much more than the others. And so on. The chapters are written to reflect this.

What proved central to the work was a single image, an image that came to be known as the *David* image. Unintended and unanticipated, this image became the centrepiece for the group members, the reference point for all the other images they worked with and they would return to it again and again. Consequently, each chapter begins and ends with this image. Equally important was the drawing in of their own lives into their work with the images – a very critical (and political) turn, but also an exceptionally personal and embodied response to the work. So very many times I was incredibly moved by the emotion and intensity with which Robin, Bob, Donna, and Sam engaged in the work, and that which was evoked by the work – expressions of such that were both spoken and unspoken, but always heartfelt. I was captivated by the manner in which they would handle the photographs: how they would hold, caress, and protect them; how they would, conversely, reject and push the photographs away.

I thus felt it imperative to structure my telling of the work with all of this in mind – to stay as close as I possibly could to the many braided strands evident in the work. Each chapter is written the same way: I write about fragments of discussions (but not chronologically) in the present tense, revealing the process of the work. I write myself into the text for to not acknowledge my part in the process would be disingenuous at best. The text unfolds as a group narrative, the story of the work being told by me but giving precedence to the voices/words of Bob, Sam, Robin and Donna. The different logics and languages of the various theoretical strands are also written in but these are secondary to the group members' languages and are most

evident in my summaries of each section within each chapter. Also included are a limited number of text boxes containing fragments of journal notes I made during and immediately after the meetings. Some contain descriptions of what was happening at a particular moment that I felt to be significant to the process of the work. Others contain my unspoken musings. The images also, I felt, needed to be visible in this telling. Bal (2004:3) demands attention to this “compulsion to illustrate”, suggesting it can become a problematic act of complicity in the reproduction, collusion, and/or reveling in acts of display. Reading this in the light of my own experiences with the public use of my daughter’s image gave me pause, yet a further reading of Bal (and others, for example, Sliwinski, 2004) suggests that a moralistic taboo prohibiting the reproduction and viewing of unwanted photographic displays is “facile and unproductive, while it makes invisible things that might matter” (2004:4). I reproduce the images in these chapters as a means of engaging the reader in the *PhotoChangers*’ understandings of what in the images matters, and why it matters (Bal, 2004). Each chapter thus includes a copy of each of the original images being discussed in that chapter. In addition, at times I juxtapose images (when, for example, the group members are contrasting different images), or include cropped versions that emphasize the feature of the original image the group members were working with at that point in the text. In some cases, the size of the images is adjusted to reflect what is being said and/or the weight of emotion behind it. This inclusion does not serve the purpose of a visual analysis of each image, rather these pieces bring something else, something more, to the overall work.

I make no attempt to mask or minimize the reality that what was developed, the ‘product’, emerged from my interpretive engagement with the group members’ work and is, as a result, quite specific to them/to us/to this particular research experience and our particular research

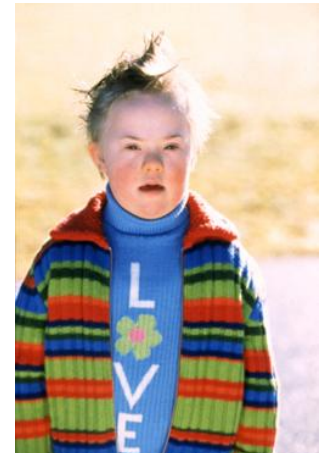
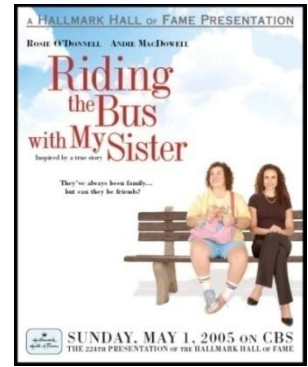
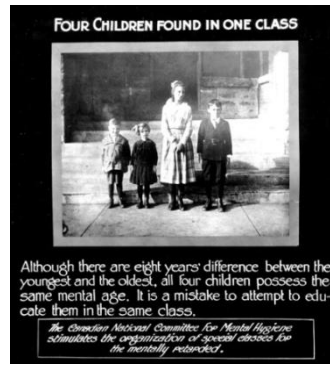
relationship. It does not reflect all people with intellectual disabilities for the ‘results’ would undoubtedly differ if the research had been conducted with a different group of people with intellectual disabilities and/or had been conducted by someone other than myself. We each brought something particular to the research spaces and relationships that inevitably (and quite powerfully) affected its outcome. I willingly acknowledge and understand that this piece of work, like all researching and all re-presentations, is incomplete, merely a fragment (Cole & Knowles, 2001), and that it reflects the choices that I made from the multiple possibilities for researching and re-presenting research. But, I recognize, too, the degree of my (I hope, responsible) attentiveness to what the group members said and did; the depth of my work with their work; and, in particular, the depth and power of that work – the group member’s intense, focused, and thoughtful engagement with the images, with the questions, with me, and their investment in the project.

What's Wrong With This Picture?

Section 2

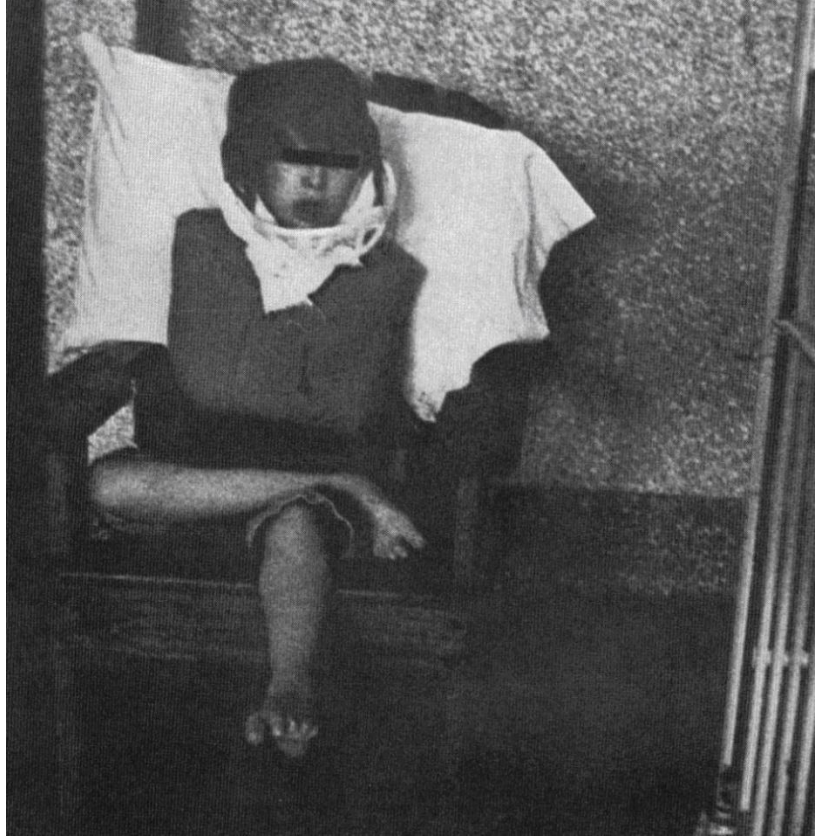
What's Wrong With This Picture

Chapter 7 – The Images





Taken from a national Canadian newspaper, *The Toronto Star*, in January, 2001, a captioned version of this black and white image (one of three accompanying a feature article) preceded the written text of the article. The text was written by Sandra Shields, the sister of the man in the image, and concerned her relationship with her brother and his role in their family. The photographer, David Campion, is Sandra Shields' husband, the man's brother-in-law. Both gave permission for the image to be used in this project. Prior to the group members working with the original image, the newspaper version had been digitized and de-captioned and the group members were each given an 8X10 good quality copy of the image as it appears above. To begin, the group was told nothing about the origins; only that it was taken from a national newspaper.



This black and white image was taken from the book, *Christmas in Purgatory*, written by Burton Blatt and Fred Kaplan (1974). As social documentary, this book was a collection of photographic images and essays about the institutionalization of people with intellectual disabilities in Westernized countries. Many of the images in this collection (including this one) were taken with a hidden camera by the photographer, Fred Kaplan, when he and Burton Blatt visited an institution in the United States. My use of this image falls within the Fair Dealing exception of *The Canadian Copyright Act* (Bill C-42). Bob, Sam, Donna and Robin were given an 8X10 copy of digitized version of the image – the poor quality of the original impacted upon the quality of the digitalized version. They were told only that the image came from a book about people in institutions.



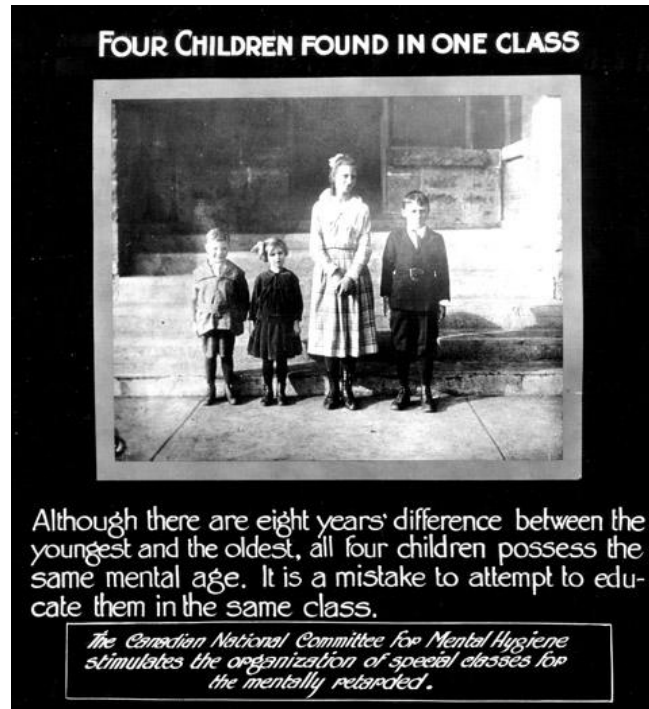
As the lead-in to a feature article in a national newspaper, *The National Post*, this colour photograph by Carlo Allegri was one of two images accompanying the article (January, 2001). The text considered the situation of the young girl in the image alongside that of Tracy Latimer (a young girl with a similar disability who had been murdered by her father). My use of this image falls within the Fair Dealing exception of *The Canadian Copyright Act* (Bill C-42). The image was digitalized and de-captioned and an 8X10 good quality copy given to each group member. To begin their work, they were given no information about the image other than it having been in a national Canadian newspaper.



Part of the *Sunflowers* advertising campaign of 1998, these two colour images were part of a collection of four produced by photographer, Oliviero Toscani, for the *Benetton* retailer. Taken at the St. Valenti Institute in the Bavarian Alps, they were used for promotional purposes and displayed in corporate materials, including large posters in all *Benetton* retail outlets. The images did not include a caption, only the *Benetton* logo. The versions shown here are the versions given to the group to work with. As permission was granted by *Benetton* to download the image from their website, the quality of the copies was quite good. The logo had been removed before 8X10 colour copies were made. Visible in one of the other two images is a name on a piece of clothing worn by the subject of the image – early into their work with the image, the group members became quite curious about this name (which is not legible) and, to move the work forward, I provided them with the information that the images had been produced by *Benetton* and the suggestion that this is what was written there.

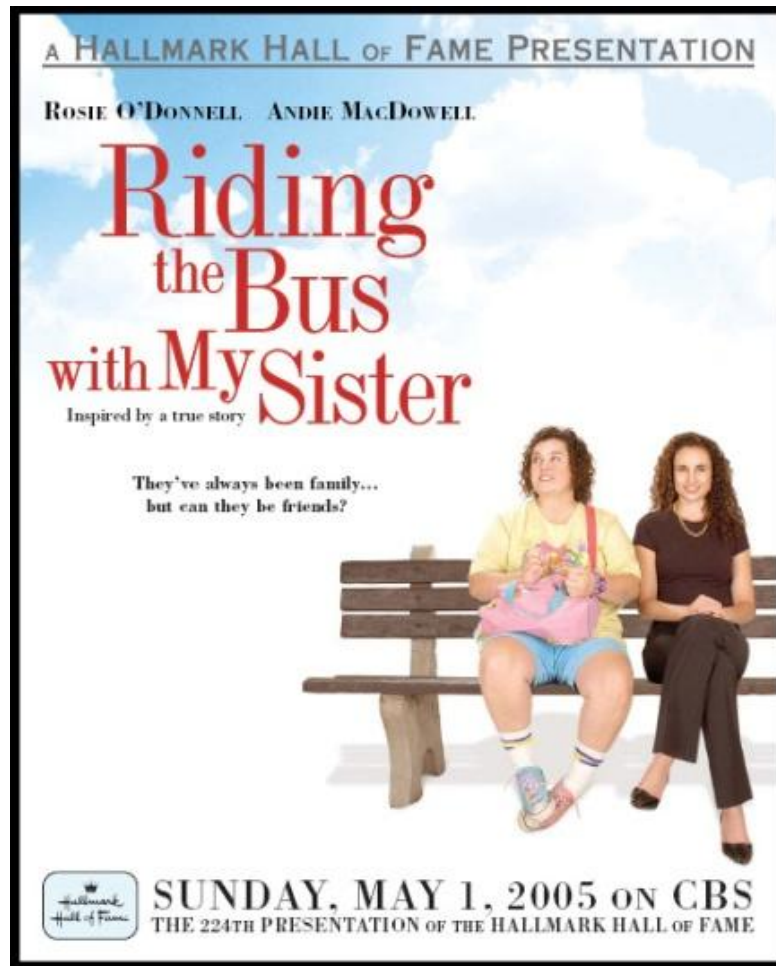


Dating back to 1985, this black and white image was produced for use in a local fund-raising campaign by the *York South Association for the Mentally Retarded* in a mid-size urban municipality (no photographer is credited). The six individuals photographed were all, at the time of the image's production, being supported by that social service agency. A caption and brief text accompanied the image. Permission for the image's use was granted by the two surviving subjects of the image. The agency believed it was up to the subjects of the image to grant permission, not the agency itself. Copies were made from the above de-captioned digitalized version of an original print copy of the image, cut from a 1985 newspaper; consequently, the quality of the 8X10 copies was poor. Donna, Sam, Bob and Robin were given no information about the image as they commenced their work with it.



The oldest image used in this project, this one dates to the 1920's. It was located in the Toronto archives of the *Canadian Association for Mental Health*. A poster image, it has been photographed in black and white. Copies for the group members were made from a digitized version of the image. Without caption or text, the original image so strongly resembled a family photograph as to create confusion among the group members as to the reason for its inclusion in a project on public photographic images. Struggling to adequately explain the social hygiene movement to the group members, I felt compelled to include the image's text from the outset, contextualizing both image and text within a brief description of the social hygiene movement's understanding of segregation as one means of improving the genetic strength of the social stock. As a consequence, Robin, Sam, Bob and Donna possessed a fair amount of information on this image's cultural production and location before beginning their work with it.

Permission to reproduce the photo granted by Centre for Addiction and Mental Health Archives.



This colour image is the advertising poster for a *Hallmark Hall of Fame* made-for-television movie, televised for the first time in North America in 2005. A digitized version and permission for the image's use was provided by a representative of *Hallmark*. No photographer was credited. Provoking much excitement among group members, the information that the de-captioned image was drawn from a movie poster spurred them to request the full text at an earlier point in their work with this image than was typical for the other images (the *CAMH* image being the exception). Providing them with the fully captioned original, the text was read by/to them but no additional information was provided until they had worked through all of the questions.



The photographer of this black and white image was Diane Arbus. The image, without any caption or text, is included in the book, *Untitled*, a collection of her work produced posthumously in 1995. All the images in the book were taken at institutions for people with intellectual disabilities in the northeastern United States in between 1969 and 1971. My use of this image falls within the Fair Dealing exception of *The Canadian Copyright Act* (Bill C-42). Copies of the digitized version of the image were prepared for the group members to work with. The quality of these copies was good. They were told that the image was drawn from a book about people with intellectual disabilities in institutions.



These two images are also drawn from the *Benetton Sunflowers* advertising campaign of 1998. As with the first two *Benetton* images used in this research, these two colour images were used for promotional purposes and displayed in corporate materials, including large posters in all *Benetton* retail outlets. The version of the images I was given to use by *Benetton* did not include a caption, only the *Benetton* logo. The versions shown here are the versions given to the group to work with. Again, the logo was removed before 8X10 colour copies were made available to the group. As addressed previously in the introduction to the other two *Benetton* images used in this project, the group members were informed that the images were produced by the retailer, *Benetton*.

Chapter 8 – Bob’s Blanket: Responsible and Responsible Caring

Introduction



Bob: I’m feeling sad about this guy...Because he’s only got one arm in the picture (there is a pause as he contemplates the image he is holding in his hands), arm is cut off...He might be in some kind of group home where they just don’t seem to care about him...He’s institutionalized and there’s only staff around and they don’t seem to care about him and he’s locked in this dark room alone, by himself. I think that’s what it looks like, an institution.

To look at him, Bob did not, at least outwardly, appear overly disturbed by the image of *David* – his facial expression, while thoughtful, betrayed little. Even when he began to speak about the image, he was not as visibly distressed as were Donna, Sam and Robin. (Donna could not bear to look at the photograph the first time I presented it to them.) Yet Bob would carefully hold the image with both hands and his gaze seldom strayed from the image for long as he spoke. The image is bare/barren – little has been included, what has is bleak. *David* has been similarly staged - photographed almost completely naked he wears only a diaper. He is alone, with naught but a plastic-protected mattress and a blanket. Photographed in black and white, the image is dark – the bits of light contained within have been pushed by its dark walls towards the centre of the image, concentrated upon the mattress and the diaper worn by the man, by *David*. In this small fragment of his initial response to the image of *David*, Bob identifies the image as a site of

care, but care that is oppressive. In his reading of the image (which took place over a number of meetings), he moves back and forth and between the image, his storying of the life of the man in the image, and his own life. Bob evokes notions of care; of being (un)cared *for* and (un)cared *about*. He suggests that, as a person with a disability, *David* is vulnerable and, while he requires loving care, he is not receiving it; neither from those charged with his actual care, nor from this visual representation of him. Paralleling the somber tones, the sparseness of the image, *David's* life is imagined by Bob to be similarly dark and empty. For Bob, 'care' (in particular congregate and segregated care) often hurts – it precludes being cared for or about in the ways Bob desires. In this above fragment, he reveals his sense that it hurts physically – Bob initially believes that *David's* arm has been cut off – but it also hurts emotionally as Bob sees *David* as being unloved, uncared for, isolated – first in either a group home or an institution, and, then, ultimately, by being left alone in the dark, abandoned in and to the image. As he works with the image, what is made plain is the divide between the dependant person with a disability and the non-disabled, uncaring carer, between the object of the image and its production.

I have entitled this chapter, "Bob's Blanket". I make use of the metaphor of a blanket to encapsulate the manyness of meaning of 'care' and persons with intellectual disabilities – Bob's work with the image befits and powerfully directs me towards its use. Bob and the rest of the group address the photographer's inclusion of a blanket in the image and, later, make symbolic use of a blanket in their treatment of the image. As critique, the blanket also opens up the possibility of new meanings; meanings set in relation to those they see inscribed in the original image. Bob and the others seem to recognize that 'care' can be helpful (desired, appropriate, ethical) or hurtful (stigmatizing, oppressive, and unwanted). Likewise, a blanket can comfort, warm, protect and cover or it can be used to suppress, smother, hide or harm. There are many

considerations to the group's understanding of visual representations of 'disability' and 'care' (and visual re-presentations *as* care) – included are questions of vulnerability, protection, love, touch, covering, and their unfortunate converse. Triggered by their engagement with the visual images and their critique of the images as sites of care or oppression, the complexity and pervasiveness and primacy of notions of 'care' in the lives of people with intellectual disabilities is revealed as an ongoing tension in Bob's life and in the lives of Donna, Sam, and Robin. This is poignantly expressed in their work with the image of *David* but, as will be seen, also exerts its hold on their work with all of the images.

Seeing Vulnerability, Dependency, and the Need for Care



Ann: What is this picture about?

Sam: Well, it's just only a kid who's just a very, very mentally disabled, who has a mental disabled and, uh, also he just, um, he's, he's just has like a poor habit of a situation that he hasn't been eating, um, like for over like a couple of months, who hasn't eaten in a couple of months, and who really is at a health risk.

Donna: I think it's about a man with a severe disability, and he's got to have someone look after him for 24 hours, but I'm just wondering if he, if he lives in a nursing home?... [he] looks skinny because maybe has a health problem.

Robin: [people with a disability like *David's*] don't have enough food, can't take care of themselves and things like that.

As they begin their work with the image, I am curious to learn just what they see when they look at the photograph of *David*. *David's* thin, frail, and bent body has been made the focal piece of the image and the group is immediately drawn to it. They remark upon its positioning, its shape

and size – “skinny”, “crooked”, “crippled”. In their initial apprehending of this image they also shift their gaze from the image itself to attend to the (real) man who has been photographed and to the story they believe the image tells about him. Sam, Donna and Robin (like Bob) understand *David* to be vulnerable and, thus, in need of care. Looking at the man in the image with grave concern, Sam sees, instead, a child – a very vulnerable child – who is at risk. From his appearance, he concludes *David* has an intellectual disability but it is the not eating that creates a health risk. Picking up on Sam’s identification of *David’s* disability, which she believes to be severe, Donna connects it directly to his need for around-the-clock care, the kind of care provided, perhaps, in a nursing home. Struggling to even look at the image, while simultaneously pulled towards it, she, too, remarks upon *David’s* physical condition, his thinness, but questions whether this is the result of a health condition as opposed to not eating enough. Speaking last, it is Robin who is most explicit in linking *David’s* impairment to his reliance on others for care – what he learns about *David* from this image is that his impairment is such that he cannot manage on his own, he can’t take care of himself. For someone with an impairment like the one they perceive *David* to have, Sam, Donna, Bob and Robin seem to regard impairment, vulnerability, dependency and the need for care as co-extensive.

Sam: ...it’s just very hard for him because he doesn’t, he’s not really that strong, he’s weak.

David’s dependence is largely unquestioned: his impairment is real and it poses barriers - *David* cannot, in any great measure, do for himself, or direct others towards the provision of that which he must have.

Bob: That’s how he is.

Robin: ...can't take care of themselves and things like that...he has mentally challenges, it has to be worked on.

Bob: ...he can't move as much...he can't function...

As they speak, I wonder whether this is indicative of their inculcation into and adoption of those dominant pathologizing discourses that, in stigmatizing vulnerability, dependency and the need for care, serve to devalue impairment and disability. That they have fallen prey to the ableist production of people with intellectual disabilities in public photographic representations? As they work with the image, their responses to the image make clear they regard it as one of excess yet, for the group, *David's* dependence is a taken-for-granted truth, and is understood to be different than that of differently disabled people or the (inter)dependence of non-disabled people. They identify with *David* to the extent that they have impairments too, and these impairments similarly create problems for them. As Donna emphatically, and even angrily, states;

Do you think if I didn't have a disability I'd be here right now?

With an empathy seemingly born of this shared identification as disabled, the group does not however always appear to construe this dependence negatively.

Robin: That's how he was born, like that.

Bob: Some people are like that.

Robin: That's how they are.

Donna: I don't think there's [anything] wrong with anybody who has a disability, I don't find – you're born like that, that's the way life is. God made you like that. You can't do anything about it.

Paraphrasing their ongoing discussion; some people are born with a disability, or become disabled – it could happen to anyone. Sometimes that means they need help. There's nothing wrong with that! For Bob, Sam, Donna and Robin, *David's* need for care is unremarkable. What is critical is what this need for care can lead to.

(Un)cared For: Abandonment, Segregation, Containment = 'Bad' Care

Bob: Maybe he's in a cell....The way it is set up it looks like a group home or a cell.

During this discussion, Bob told us of his beloved girlfriend, L. L. also had an intellectual disability and lived in a group home. Bob loved her dearly. She died of meningitis. Although this happened many years ago, he continues to mourn for her and has never had (nor desired) another relationship with a woman. I want to ask (but fear being invasive) if Bob believes that L. was not cared for properly? Is this why he believes she died? Is this part of his concern for David and his wanting to protect him? Or, does the scene in the image simply resemble his internal picture of an institution? (I find out, in another meeting, that Bob knows all about institutions and the oppressive treatment accorded residents – he has friends who were involuntarily placed in them.) Is it both? Or, is it something else entirely?

The group identifies *David* as needing care but, as Bob made clear, *David's* corporeal vulnerability also leaves him “open to attack or damage” (Hasler, 2004:230). Responding to how they feel the image has been set up (and also to how the object/subject of the image has been ‘set up’) to convey the idea that this seemingly very vulnerable man is in a group home or incarcerated in a cell, the group’s concern over *David's* need for care is matched, if not exceeded, by their worries that the care he requires is not being provided, is inadequate or, worse, might actually be harming him.



Holding the image tightly in his hand, a serious and distressed look on his face, Sam poignantly

says:

I have a sensitive heart...What can I say about the picture? All I can describe is that it's very hard for me to look at, hard to look at.

Sam wants not to see this image. The image of *David* is painful to view, painful because Sam, Robin, Donna and Bob look upon *David*, not as an object, nor even as the subject of this photographic image, but as a real person – a real person who, like the four of them, has a disability. Throughout their work with this photograph, they discuss the man in the image in this manner:

Donna: I would really like to meet him, in real life, talk to him, see how he is doing.

Engaging not only with the image, but with the man within it, Donna expresses her desire (and her assumption that this would be possible, that *David* does exist) to meet and talk to David. Donna, like the rest, wants the opportunity to know *David*, and to let *David* come to know them. She wants to “shake his hand” and “give him a hug, for support”. Theirs is a caring gaze; they are concerned about him. Emerging from their initial discomfort, they want to see more, to learn more about *David* from the image, to see the layers of *David's* life as it were, yet these have been deliberately hidden from the viewer and this puzzles and frustrates them - they beseech me for answers, assuming that, as the researcher, I must know *David*, at the very least I must know all about him. Holding *David* in their gaze, as they hold the image in their hands, they reveal their care and, too, their outrage that others are not similarly caring. The image is distressing, painful and hard to sustain. Undone by the image, the group struggles with, what is for them, the im/possibility of its truthfulness – it is not possible (or is it?) that people could *not* care so completely as this; could be so indifferent as to let this happen.

Sam: What happened to the boy and why is, what's it called, is he sitting out here on a blanket and he's all naked and why is he wearing a diaper, and what is, honestly, wrong in what happened to him?

Seeing vulnerability, dependence and oppression (rooted in this dependence) in the image, Sam appears genuinely confused as to why *David* had been put in this situation, distressfully looking to me and to the others for an answer. Wounded, unable to come to grips with what they see, the group is trying to find, or to create, a story about *David's* life, a reason or causal chain for how he got to this particular place. Having been exposed to this image, asked to re-think this and other public photographs of persons with intellectual disabilities, they are also trying to find meaning, to create a story, about the image itself and *David's* place(ment) in it. It is unfathomable that *David* has been left like this, that there is no-one taking care of him. It is unfathomable that he has been photographed this way. Sam attributes *David's* plight to both personal and social factors, a function of his physiology *and* the response of others to him. He does not believe *David* is being properly looked after: he is not being fed; he's not adequately clothed - wearing "just a diaper" he is "half-naked"; and, by being left "out in the cold", he is not protected. He is alone in the image and, to their minds, in life. Discarded and exposed these ways, he has been stripped of his humanness.

Robin: He's not eating enough, the food, that's what causes him to be like that...It's just scary, not the whole thing, just some of it, it's sad that he's not eating enough, that's all I could explain it to you about it..

Robin (repeatedly) furthers Sam's attention to nutrition as an indicator of care, but his more insistent focus initially suggests he is attributing *David's* situation solely to his being malnourished. I wonder if it is really this simple for him. He admits to finding the image scary - is the image so frightening that he latches onto this idea as a means of explaining it to himself, of understanding it? *David* is understood by the group to be as vulnerable as an infant. Culturally,

photographs of babies on/in blankets are typically images of happy babies, of babies playing, sleeping, or being held, cradled and comforted while wrapped in a blanket: while pointing back to such images, this image also runs counter – portraying *David*, instead, as abandoned to the blanket, a blanket that proves an insufficient provider of care. As we talk further, what becomes clearer is the degree to which Robin was disturbed and saddened by this image and his belief that *David* is mal-nourished in a broader sense: to his detriment his need for love, helpful care, and nurturance was not being met.

As has been shown, the group worries a great deal over the risks posed by *David*'s physical fragility, his consequent need to be kept safe and to be protected, and their unshakeable judgment that he is not being taken care of – that the ‘care’ he is receiving is hurtful rather than helpful. Their concern escalates as they spend more time inspecting and questioning the image, for the more they look, the less (good care) they see. Asked what they see when they look at the photograph, they overwhelmingly see ‘bad’ care. His voice registering distress, Sam says:

It looks like he's outside on the ground...almost like he was in the desert or something.

...like he's been buried alive!

...in a very unhealthy situation.

...as if he were dying!

It could lead you to some kind of bad, um, what's it called? A bad luck and a bad health condition – it's very bad, you know, very terrible.

Sam's words, and the anguished tone with which he utters them, reveals his struggle to make sense of what is happening to *David*, to make sense of his suffering. Sam articulates this eloquently as he expresses his interpretation of the very vulnerable *David* as being abandoned, dangerously, to the elements. His feeling that *David* is in an “unhealthy situation” and looks “as if he were dying” reveals a consequence of the hostile type of ‘care’ or ‘un-care’ that involves neglect or abandonment – there is no-one available (or willing) to save *David*, no salvation for this very vulnerable man. Suggesting *David* has “been buried alive”, that he is “dying”, implies

something (more) sinister – that the ‘care’ he receives is little more than a cover for euthanasia. Yet these conclusions, the meanings he unearths in his reading of the image, are not acceptable to Sam. They cannot be absorbed. He cannot acquiesce to them and this moves him to a feeling of closeness towards the person in the image – to a feeling of being called to protect *David*.

Donna was the first to explicitly identify the actual blanket in the image:

He’s lying on a blanket on the floor...He doesn’t look happy, to me, that’s the way it looks to me, like he’s not smiling or nothing...Somebody must have picked him up and put him on the blanket because he can’t walk.

She carefully attends to certain details in the image – the wrinkled blanket and its placement on the mattress directly under *David’s* body, *David’s* unsmiling face and supine body – and attempts to reconcile the contradictions she sees there. Despite the presence of a blanket, Donna does not perceive *David* to be cared for, as is indicated by his apparent unhappiness. Having been carried to the blanket by another, he has been put in this situation, presumably against his will. The blanket triggers other associations (physical and institutional) that hearken back to the group’s confusion over whether what is happening to *David* in and through the image is care or abandonment. Initially, Bob recognizes the blanket as a protective element in *David’s* situation:

...the blanket...because, in case he falls or has another seizure, he might bang his head - that could be dangerous.

In another meeting, I inform the group that the man in this image had a very serious seizure disorder, and that these seizures continued to cause damage to his brain. They were all quite upset by this. Donna, expressing both sadness and fear, tells us of a woman she knows with a seizure disorder. Medication has not been effective in managing these seizures and they are harmful and disruptive, taking a toll on the woman’s health and on her ability to live her life the way she would choose to. Seizures have a much greater significance for Bob. Upon hearing about the seizure disorder, he says, “oh, no”, and then, quietly and simply, he tells us that his mother died of a seizure. Despite their assurances to the contrary, I worry that this work might be too personal and more difficult than they anticipated.

While, on tape, I can see only his hand moving in and out of the video camera's frame, Robin gesticulates for emphasis in support of Bob's interpretation. Robin also feels that the blanket will keep *David* from falling. And, as the discussion continues, Sam decisively adds to the list of possible dangers lurking around *David*. For Sam, the blanket functions to protect *David* from the effects of the hard ground he lies upon in this cell or institution – a surface that is not good for his frail body. The blanket will shield him from harm, a harm the group seems to regard as both imminent and already apparent in the image.

Clearly, Bob and the others hold contrary views about the blanket and, by extension, about care. Further expressing their distrust of the 'care' being accorded to *David*, Bob (with a tone of alarm and consternation, flipping the image back to front as if looking for the answer, for something else, something more in the image) asks:

Why is he not smiling?" "Why are they laying him down on the blanket?"



He echoes Donna's concerns yet his agitation suggests he is becoming increasingly disturbed by what he sees:

It looks pretty scary 'cause I think he's still institutionalized, like the blankets make him look scary, the walls around him, looks like he's institutionalized. And his hands look very, uh, not very good and he's all skinny and he's wearing a diaper.

Bob is very explicit here – attending to the staging of the image he puts more of the details together to find meaning in it. He labels the blanket in the image as threatening and as a marker of a lack of care, but the blanket is but one element of the oppressive and frightening picture of care that Bob holds in his mind. As he speaks, he points to different pieces of the image. The bottom, top and sides of the image, and the carpeted area around the mattress, resemble walls and suggest that *David* has been discarded to a jail cell, left alone with this inadequate provision. For Bob, other markers of care as oppression include the institutional setting, the state of *David's* physical body (his hands, his thinness), wearing only a diaper and not smiling. *David* is not happy with the way he is being (un)provided for – his facial expression is, for Bob and the rest of the group, evidence of such. As it did with Robin, the image scares Bob; the situation that *David* is in is a frightening one.

In this fragment, Bob has returned the group to the notion that *David* is institutionalized. As he tells me during his work with another image, for Bob institutionalization is the penultimate marker of 'bad' care; the abuse of people with intellectual disabilities second only to their murder. Interestingly, Bob says that *David* is "still" institutionalized. I am confused as to his meaning. Is he referring to de-institutionalization; suggesting that *David*, unlike other people with intellectual disabilities, has not yet been moved into the community and remains confined to the institution? Does he regard the image itself as a tool of institutionalization, of constraining our knowing of *David*? Is he suggesting that somehow, if we look at the image long enough, that this might change? Or, is this an attempt to assert his opinion, that no matter how the others interpret the image, Bob will not be swayed in his belief that *David* is institutionalized? Bob is

quiet and thoughtful during our meetings, respectful and often (even perfunctorily) deferring to others, and not likely to openly challenge them. Is this quiet insistence a means of ensuring his voice is heard? As I gently press him to elaborate, he confirms the latter – he just wants to be heard and to have it understood that this is his enduring perception of this image: *David* is in an institution.

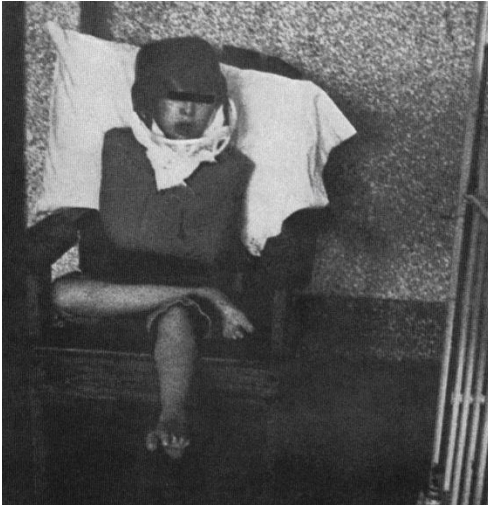
When asked how he thought non-disabled people would react upon viewing this photograph, what they might think it said about people with disabilities, Bob replies:

Some [non-disabled] people might not like it because they might think, definitely, this guy's institutionalized, they might think that, that that's why he's like that, 'cause he's institutionalized.

In trying to make sense of what he sees in the image, Bob arrives at an explanation, a point of causality. He explains the *David* we are given to see as being a 'result' of institutionalization – he is as he is *because* of the 'care' he has received. This is the 'truth' Bob unearths, a 'truth' they seem to have, till now, resisted seeing. Bob is quite direct in charging institutions with doing this to the people who are placed in them, laying blame at the feet of professional decision-makers and care-providers: *David* looks 'like that' because that is how people are (un)cared for in institutional settings. Here he challenges disability and impairment as biologically determined states of being – this has been done *to David* and is, thus, a choice made by those providing care: the responsibility lies not with *David* but elsewhere. I am surprised that, at the same time, Bob seems to credit the non-disabled viewer with approaching the image with the same careful/careful and considerate gaze, and with (inevitably) coming to the same conclusion.

Before moving forward with the group's work with *David*, I would like to offer, here, another image central to the group's evocation of 'care' as oppressive, as 'bad', and central to their telling of the story of the *David* image. In their careful/care-ful gazing and consideration of the

David image, Bob, Sam, Donna and Robin draw upon many other images along the path towards their storying of *David*.



Upon first being presented with this Burton Blatt image, Donna's discomfiture is clear. In an exaggerated movement, she averts her gaze and wags her finger at the image in a gesture reminiscent of scolding a young child; as if the photograph, itself, by making her confront such an image, has done something wrong.

Donna: Yeah, I like that one better [pointing to another image]. I don't want that one [Blatt], I do not want that one. Sorry..."

Both Bob and Donna quickly ascertain the child in the image was photographed in an institution:

Ann: [pointing to the image] There's a little girl, and where do you think she is? What can you see?

Donna: She's in an institution.

And later,

Donna: Uh, she's sitting down, it looks like she's got a pillow behind her, um, sitting up, and it looks like she's just sitting there, um, and she's not happy at all! She doesn't look happy in that picture..

Ann: OK.

Donna: ...she looks like she's sitting in a wooden chair, and just sitting there and relaxin' and, and, have the pillow behind her.

Ann: OK, what kind of chair do you think somebody would be sitting in if they have a straight-jacket on? What kind of chair do you think that would be, if they're wearing a straight-jacket?

Bob: Oh, she might be institutionalized.

Ann: Yeah, yeah she is.

Bob: That was a good thing to say! 'Cause it looks like there might be some bars there [pointing at the image and looking for confirmation from myself and the others].

Ann: Yeah, it does look like bars, yeah.

Bob: OK.

Ann: OK, right. OK. When you guys, um, look at this picture what's the first thing that jumps out at you, what's the first thing that you see?

Donna: I see the bars.

Bob: Right.

Robin: The bars on the right side [of the image].

Ann: Is that what you see, too, Robin?

Robin: She's probably like in a jail or something, or in prison where they're keeping her.

Ann: OK. What is it about the bars Donna that you notice?

Donna: It looks like, it looks like a jail, where you have, you have, behind bars, it looks like, it looks like a jail cell.

Bob: Right.

Donna: That's what it looks like to me.

Robin: She's locked up, she can't see anything.

Ann: OK, OK.

Donna: No windows, no nothing.

Sam: The thing that I see on her eyes and a way about her, um, face looks because she's very, um, upset and she's really feeling sorry for herself and also she's wearing, because she's wearing a straight-jacket.

As with the *David* image, they do not believe the child in this image to like what is happening to her. As Donna notes with emphasis, "she's not happy at all"! Indicating the bars framing the right side of the photograph, Bob, Donna and Robin understand the child to be imprisoned – Bob believes she is in an institution, however, Robin asserts she is in jail or prison, and that she is being kept against her will. It is these locations that explain to them why she is further contained by the restraint chair and the straightjacket, and why she has been left alone. Locked up like this, she is prevented from seeing anything (although there is little to see in the image beyond the bare wall, floor and bars surrounding the child). This image has been photographed in black and

white and, as with the *David* image, is quite dark. The graininess of the image (a result of having been taken with a hidden camera) further works to blur the specifics and complicate its reading, yet the group members seize upon those details that they can see and that direct them towards the construction of their story, the fulfillment of their desire for a story to make sense of what they see. All of these details are understood to contribute to the girl's containment, to being barred from seeing (and from being seen), from movement, from escape.

The mood of this image, like that of the *David* image, is somber, bleak. In their work with this image, the Sam, Donna, Bob and Robin start with and stay in this particular register. Their responses to the image are emotional ones. Bob is especially troubled by what he perceives to be happening to this child. He is saddened by it; an emotion he believes is shared by the child in the photograph. As well, he is concerned as to how viewers will interpret the image but, in contrast to his crediting audiences of the *David* image with recognizing the social causes of *David's* impairment, in the *Blatt* image Bob believes the child will, unjustifiably, be held responsible for her situation and her treatment erroneously understood as a reasonable response to the girl's (presumed to be bad) actions:

Ann: OK. What about you Bob? What story do you think the picture tells?

Bob: It makes me feel sad, uh, because the girl is – it looks like that she's tied up to the chair, I think she's sad that they've tied her up, and she can't move, [non-disabled caregivers think] they've [people with intellectual disabilities] done something bad or something naughty, that's why they're tied up like that...

Ann: OK.

Bob: ...but they're [people with intellectual disabilities] really not [bad, naughty] and they shouldn't be institutionalized!

Bringing the details of the image to bear on his explanation for the girl's situation, Bob suggests the possibility that some ordinary (perhaps even necessary) act or expression by this child has been so misread, so misunderstood by her non-disabled carers, as to lead them to perceive her as

bad and to confine her so horrifically. The group's conversation unveils their conviction the child (and, in Bob's use of the plural "they", *all* people with disabilities) is being punished and, because non-disabled people regard people with disabilities as, somehow, 'bad', their vulnerability, disability, and need for care are consequently used against them in excessively punitive ways. But Bob notes, too, that the image lies; constructing as 'bad' people who have done nothing wrong. In a mimetic turn, because of their knowledge that they share the label 'disabled', this slippage between the image and their own lives concerns them greatly.

This image is particularly unnerving for the group. Understanding the child's treatment to be an egregious wrong, they are surprised and upset and even outraged that someone could, and would, do this to a person with a disability, especially to a child for whom her young age only exacerbates her vulnerability. Indifference is not an option - they revolt against the notion that non-disabled others might feel justified in their treatment of this child. Their feelings intensify as they ascend ever deeper into the image over the course of their many discussions of the photograph. In one of their last conversations, their refusal to surrender to the un-truth of the image is vividly captured by Sam:

Yes, absolutely, what I would actually like to say is this a little girl who is being in a cell and she, ah, she's been put on a straight jacket, and the thing I don't like about this picture is that she is wearing a straight jacket and that it makes her feel uncomfortable and she feels so bad and she is only just a child with a disability or Down's syndrome kind of thing, and even sitting in a wooden chair and trying to torture, or trying to torture the child, abuse the child or punish the child for no particular reason, but if there is a better way to treat a child appropriately than putting her a straight jacket - that is not the way to do it, you know! That is not the way to treat a child because no child has the right to be treated this way, because if the child has a disability or something they have another way to help the child to make gets things better for herself and to get more knowledgeable and, the patient way. For that matter, it is more appropriate, they don't have to be so mean and cold-hearted that way! I don't believe in kids wearing straight jackets - that is the most depressing thing and it is hard to listen to and hard to see as well! It is not fair!

Ann: If you were somebody who did not have a disability, and you saw this picture, what do you think it would tell people about people with disabilities?

Sam: What would this tell about people with disabilities? What this would tell - as a matter of fact, I don't think this would be the right way [to tell about people with disabilities].

Ann: Do you think it would tell them that this is supposed to be what you do with people with disabilities?

Sam: No no, absolutely not, no! [this is the story the image tells but this should not be done to people with disabilities.]

Empathizing with the child (the straightjacket makes her feel “so bad”); Sam’s reaction is a deeply felt one. Not only has the child been incarcerated in a cell, she is also put in a straightjacket and made to sit on a wooden chair – punished for no particular reason that he can ascertain. Becoming increasingly angry, he reacts to what he labels the “torture” of a little girl by “mean and cold hearted” people and vehemently argues against it, citing it as a violation of her rights. He is insistent that there is a better, “more appropriate”, and “patient way” to help the little girl: in Sam’s view, this is what she requires – help, not punishment. For Sam (like Bob), what is most painful is the realization, not only that a child with a disability *could* be so badly treated, but that people might actually believe this is how they *should* be treated.



The group members are confused by the seemingly contradictory presence of an object in the image, by the “intrusion of the unexpected and unanticipated” (Derrida, 2001:5) pillow behind the girl’s head and back:

Ann: OK, what about you Bob, what's the first thing that you see, what kind of jumps out at you when you look at this?

Bob: She's got a pillow.

As Bob notes, the pillow is a prominent piece of this image. Its staging influences the group members' responses to it. The pillow is quite large and takes up a significant amount of space in relation to the entire image and to the girl in the image. Its size emphasizes the smallness of the child. Its brightness – the starkness of the contrast between the white pillow against the grey walls, the girl's dark hair, the dark straightjacket, chair and floor – draw the viewer's eye to it. They feel this pillow has meaning, yet this image does not easily or satisfactorily explain its presence in the eyes of Bob, Donna, Sam and Robin. We talk a bit about whether the pillow is just to make her more comfortable or to somehow protect her, to keep her 'safe' while she is being restrained. Safe from what? From herself? They are unanimous in the belief that she is not at all safe here. In time, Sam comes to assert that the pillow is only adding insult to injury, that it is “not polite to make her feel in more of a worse situation, this was not fair”. Bob and Robin concur and find the pillow's presence unusual:

Bob: Right, a little weird.

Robin: Yes, to me, yeah.

While not entirely able to make sense of the pillow – neither its use in the girl's confinement nor its inclusion in the image - Donna and Bob (the eldest members of the group) seem to have a very clear understanding of the “rules”, the legalities around forcible confinement and its use when there is a perception of risk to self or others.

Ann: What about you, Donna? What picture, what story do you think the picture tells?

Donna: Well, (a seemingly weary pause) maybe she has psychiatric problems and that's why they put the straight-jacket on her, in case she tries to escape from the institution. Um, and um, um, in case she tries to run away or anything. And they got a straight-jacket just in case she decides to, maybe, hit herself or hit anybody

else, you know. Her toes look like they're bent in. So it looks like she's mad, like she doesn't want to be there and, and um, she's um, maybe she's in there, maybe she's in there for a reason 'cause she's got a lot of problems, you know, mental problems and stuff like that. So maybe that's why her family put her there, 'cause they couldn't handle her.

Ann: OK. So you think her family put her there?

Donna: Yeah, or her social worker if she has one (here she laughs and looks directly at me). That's all I can think.

This fragment highlights some of the complexity of Donna's understanding of institutional care, and her struggle to find meaning in what she sees in the photograph. The conversation moves forward, however Donna seems to flag – rubbing her hands over her face and through her hair, she becomes more and more disheveled as she speaks. Her body sags, weariness is etched on her face. She clearly cares deeply about the people in the images and this work is hitting so close to home – I worry she is struggling as a result but she assures me she is okay. Donna *seems* also to be suggesting that institutional care might sometimes be necessary (“just in case she decides to, maybe, hit herself”) and, thus, in the person's best interests. Pushing against what, for her, seems to be an unseeable ‘truth’ in the image, she is emphatic that the little girl does not want to be there, that in fact, she is “mad” and wants to “escape”. In her search for meaning, for the story, Donna tells me that the girl is in this position because (like *David*) someone has put her there – someone else is responsible. In so doing, Donna trembles the said of the image, the taken-for-granted necessity of institutional care for people with intellectual disabilities by simultaneously raising the notion that an important underlying question may be, “Who is being taken care of?” She articulates that decisions around care are often not undertaken on behalf of the person with a disability, but in response to the needs of others (e.g., the family). Donna questions if the girl's behaviour, her disability, might have been regarded as a burden for her carers, as being beyond their ability to manage: in this way, the girl's institutionalization meets the needs of the family, needs which override the girl's own wishes, needs, or, as Sam suggests,

her rights, and is, seemingly, justified on that basis. But this story creates for them a tension – there *might* be a reason for the girl’s having been banished from her family home (e.g., problems that were beyond the capacity of her family to manage) but this is neither the place, nor the way, to address such.

Donna also raises for consideration the role of social work(ers) in decision-making around care for people with intellectual disabilities. She queries whether the little girl’s social worker is implicated in her incarceration in this horrible place. While, in this particular conversation, there is a playful touch to her remarks (which are teasingly directed towards me), her feelings about professionals are seldom so light-hearted. Donna speaks often, in and outside of meetings, of her confusion over the behaviour of ‘helping’ professionals whom she regards as consistently failing to understand or support her. Rather than helping her, she feels punished by workers who, citing her emotional outbursts and their concern for themselves and other program participants, “kick her out” or deny her access to groups and programs she believes she needs and would benefit from.

As we continue to talk, I am, at one point, struck by Donna’s troubling of her own, and the group’s, assessment of institutions as unequivocally ‘bad’ (*italics* added for emphasis):

Ann: OK, alright, have you guys ever, um, you guys ever known anybody who lived in an institution?

Robin: No.

Donna: Well. right now I know...

Ann: Donna, did you?

Donna: Well, no, I know somebody that’s, that’s in there now, that’s, she’s been in there for, like a few years, maybe one or two years now, um, you guys...

Ann: Where is she?

Donna: ...the one’s in called, uh, um, the one there at Ossington and Queen there...

Ann: Ah, right.

Donna: Yeah, 'cause she's in there 'cause she was, she was off, off her medication and I guess she, she has some problems when she was off her medication she was always crying and, and, and, um, getting, *getting people upset* and stuff like that, so...

Bob: Right.

Donna: ...*she was off her medication so they, they put her in there* and, and, uh, she has to take her medication so they're making sure she takes her medication. But I doubt very much that she's gonna be coming out, so...

Ann: You don't know?

Donna: ...No, I think she's, she's, so far she doesn't wanna, she doesn't want to come out, *she wants to stay there*. But, you know, I'll tell you something, I wouldn't want to stay there, but, but, before she was...

Ann: Have you been there, have you gone to see her?

Donna: No, I haven't gone to see her, but I mean, like, um, um, one of the coordinators went to visit her a long time ago and she was, it was, she was a, you had to, the doors were locked so she, so nobody could, you know, nobody could come in or go out. Like, they would have to let you in and stuff like that...

Bob: Right.

Donna: ...and all that but now I think that you can go and visit her now, I don't think it's, I don't think it's a place where its locked where she can't escape or anything. 'Cause I haven't seen her for awhile, she's over 65 years old. She just had a lot of problems, uh, uh, doing a lot of crying and *getting people upset and getting mad at them* and stuff like that and being off her medication.

Donna grows more and more animated as she talks about this. I want to ask if what she is saying reflects, in any way, her own experiences with people being upset with her and not feeling safe with her, for she has talked about these often as we travel the subway home from meetings, seeming to seek reassurance that it won't happen in this group. But I don't ask – it does not seem to be the time or place.

Donna makes plain that the decision to place the woman in the institution was beyond the woman's own control: the decision was made by others in response to the effects on *them* of the woman's choice (?) not to take prescribed medication – the woman's behaviour, her anger, was upsetting to the (non-disabled) "they" and "them" who possessed the power to usurp the woman's right to self-determination. But tucked into this fragment is Donna's assessment that this woman does not want to leave, that she has come to look upon the institution as a place of 'asylum', in its traditional capacity, as a place of safety and refuge in times of stress (Milligan, 1999). (I am reminded here of Donna's earlier perception that the child in the *Blatt* image was

“relaxin.”) Although Donna is adamant that she would never wish to be in an institution, I wonder, and gently pursue with Donna, whether she believes that an institution could, in fact, be considered (by others) a safe place, a positive place that one might, indeed, *choose*? Or does she feel this is one way in which the woman is subverting the power of others over her – making the choice instead of having it made for her? From our discussions, however, I conclude that for Donna, and the rest of the group, this is just the easier solution (for non-disabled others) and reflects the group’s awareness that the larger community is not prepared/able to support the woman on her own terms (i.e., without medication). There is little doubt that Donna views the institution, *any* institution, not as a place of refuge, but one of imprisonment – I hear again (as in an earlier piece of the conversation about this image) her use of the verb “escape”.

Again, I wonder (but, again, do not ask) to what extent this discussion is a projection of her own conflict – an expression of Donna’s desire for support in dealing with the painful experiences in her own life and the fear that the response to her emotional expressions of this pain will be unwanted institutionalization and/or the stripping away of her tightly-held rights and control?

I ask Bob, Donna, Sam and Robin what the image says about people with disabilities. Bob begins at the level of the person, the young girl whose image is captured in the photograph standing in for all persons with disabilities:

...people with disabilities who are tied up are sad.

Here he is attentive to the child’s confinement, to her feelings (conveyed by her facial expression), and he extends them to all people with disabilities experiencing confinement or other restrictions. Sam tells us he feels the image says “bad things about people with disabilities”, which confuses me, but, when I ask him to elaborate, he clarifies that his statement does not imply that the person with a disability is, in any way, bad, but, rather, what is happening

to the person with a disability is bad. Moving beyond the little girl herself, he assigns responsibility to the non-disabled people charged with the girl's care. Similarly, Robin tells me that the image says both bad things - "that the girl is tied up" - and good things - "it would be good to get the straight-jacket off and to take the thing off around her neck": "it said bad things and good things - in between". Much like Bob, Robin is hopeful (although not convinced) that the reprehensibility of this type of 'care' will be immediately obvious to the non-disabled viewer.

I follow this up with a question about what should the image tell non-disabled viewers about people with disabilities?

Sam: That the girl has a physical or intellectual disability.

Bob: No-one should be in an institution, the girl should not be in an institution!

Moving squarely here into consideration of the image, into how to re-frame the image, they tell me they have no wish to hide or minimize the child's disability (the specifics of which, they point out, are hidden to a great extent by the straightjacket, the black band across the eyes, the cloth around her neck and the darkness of the image) but to transform the image as a means of expressing their attention to and caring for the little girl, and their fearsome opposition to such violent institutional care. The group tells me they want the figure of the girl taken out of the institution, the restraint chair, and the straightjacket and also to remove the black band from across her eyes. They want to free her and to be able to see her. This, however, proves too difficult to accomplish with *Photoshop*. (I want to note here that while this particular transformation was not possible, they have a second response to the image that was visually realized and will be addressed in the next chapter.)

*(Un)Cared About: Caring **For** is Not the Same as Caring **About***

What troubles the group is the fact that neither *David* nor the child in the *Blatt* image is being

taken care of. They move back and forth between their personal and social experience of the image, between their concern for what is (and is not) being done to, and for, the (real) people in the images and their wondering why non-disabled others are doing this or letting it happen; between their own experiences of hurtful care, of un-care, and their understandings of the place of people with intellectual disabilities in the larger society. How do Donna, Bob, Sam and Robin explain this hurtful treatment, the oppressive ‘care’ afforded to people with intellectual disabilities that they see represented in and by the images? Quite simply. Speaking to the image of *David*, resignation registering in his voice, Robin states:

They’re leaving him there ‘cause they don’t want him. I think he’s not wanted and stuff like that.

When I asked him why he felt *David* was unwanted, Robin sadly stated that *David* is unwanted:

Because he has a disability.

The group members are most disturbed by their belief that no-one cares *about* the people with intellectual disabilities figured in the images. Bob interjects a personal question into this conversation, asking me, “Why didn’t Frances’ [my adopted daughter’s] parents want her?” Answering honestly, I tell him that I had been informed by the adoption agency that Frances’ diagnosis of Down syndrome was the reason given by her parents for their decision to relinquish her to state care – they did not feel capable of providing for a child with disability, nor did they believe their community would accept her. At this, Donna (who has come to know and care for Frances) becomes extremely upset, and tearfully says:

That’s very hurtful, especially when your family, you give birth to a child and all of a sudden they turn around and, if my mother, if my parents said... see, when I was born with a disability they didn’t turn me down but if they hadda said, “well, my daughter was born with a disability – I don’t want her anymore”, I’d be

terribly upset. I mean, I'd be freaking. I'd be saying "hey, why'd you give me up for adoption – you're the one that give me birth. If you don't, if you don't want to give birth to me then you shouldn't 'a got pregnant, you know what I mean?"

Donna articulates what, for her, is the un-refusable obligation and responsibility of a parent – to want, to love, and to care for one's child. In Donna's words and in her voice is the expression of her own fear and distress, her feelings of being rejected (despite having been raised by her birth parents) and unwanted by her own family and by others. Bob and Sam gently comfort Donna; Sam patting her shoulder, passing her a tissue, and soothingly repeating "there, there". This caring continues as we talk, and I hear in the words of Donna, Sam, Bob and Robin, their conviction that in this world there are people who are wanted, and those who are not. *David* and the little girl in the *Blatt* photograph fall into the latter category – both have been abandoned, both are not wanted and they are not wanted because they have a disability. Abandoned as they have been to these images that are inscribed with this message, the images themselves are not sites of welcome, but of closure. They do not invite the viewer to consider inclusion but reinforce exclusion. Yet their words also point to the other side of un-care – for the group (and, they feel, for *David* and the little girl in the *Blatt* image), there is also wanting; wanting to be someone who is wanted.

Robin was very involved in this part of the conversation. Again, I find myself wondering if his child welfare background is at issue here – does he believe he, too, was 'unwanted', with the consequence of being placed in state care? If so, how does he make sense of this decision? Does he attribute this to his own disability?

Let me remind the reader of Bob's initial interpretation of the *David* image:

I'm feeling sad about this guy....Because he's only got 1 arm in the picture (there is a pause as he contemplates the image he is holding in his hands), arm is cut off....He might be in some kind of group home where they just don't seem to care

about him...He's institutionalized and there's only staff around and they don't seem to care about him and he's locked in this dark room alone, by himself. I think that's what it looks like, an institution.

Bob, too, perceives *David* as having been banished, "locked in a dark room alone, by himself". Similarly, Donna understands that in having been placed on the blanket *David* has been discarded, cast out because he can't walk. When I ask the group, "so, if you see a picture like this it means you think no-one's looking after him?", they reply "yes", and go on to explain this abnegation to be a consequence of his having a disability. What is highlighted is the degree to which they understand caring *for* a person with a disability to be dependent upon caring *about* that person: caring *about* matters. *David* is not wanted, he is not cared about. As consequence, he is not well cared for. This is the story the image has been constructed to tell. With head hanging, speaking to his perception regarding the situation for people with intellectual disabilities, Robin forlornly says, "people don't care."

The group members' affective and care-ful responses to the images – their attentiveness to the real people in the images – reflects their position as not one of gazing at, but one of caring for, and is tested by the lack of care they see reflected in and by the image. Much time is devoted to discussing just who is responsible for providing care (someone certainly must be), for caring for and about people with intellectual disabilities, and asking, "Where are those people?" Of *David*, Donna said:

I wish I could do something for him but I can't, but, um, God's probably gonna be with him and, and, and he'll be, he'll be looked after.

Speaking softly, concentrating her attention on the image in her hands, Donna attests to her own sense that *David* needs to be cared for and her own inability to do so. She tentatively proffers

that people with disabilities, at least those disabled in the way *David* is, are in the hands of God. Consequent to God's caring *about David*, he will be cared *for* by others. Talking to her further, she appears to identify group home service providers as the people commanded, by God, to provide care.

All of this I find very intriguing for her choice of God as 'David's' savior belies her own denouncement of God as such and her growing conviction that God is but a fiction – beliefs which have resulted in many (heated) exchanges between Donna and Bob on our subway rides home, but I do not pursue this here.

Donna: Who will look after him?" "Maybe the group home? You know, those group homes where people go.

I am surprised - Donna makes it sound almost inevitable that people with disabilities end up in group homes. But she herself does not live in a group home, nor does Sam or Bob or Robin. I wonder if she means that group home care is the only option for people living with impairments like the ones she understands *David* to have. Her assertion that group homes are an option is disturbing in light of her earlier assessment of group homes as oppressive, as neither caring for, nor about, people with disabilities but she does not make this connection. Becoming ever more anxious as the conversation proceeds, Donna does not explicitly address my questions.

Nonetheless, the conversation reveals, again, her underlying conviction that people with intellectual disabilities are often (typically?) unwanted, discarded by those who, by rights, should care about them and thus doomed to such oppressive treatment.

They are not yet finished, however, with the question of responsibility.

Donna: Where's his mom and dad? Where's his family? Where's his friends?

Sam picks up this thread:

Where are his relatives, or where's his guardians, or anyone who takes care of him or looks after him or something?

In doing so he underscores the assumption that 'family' is the natural and preferred choice, (an assumption, I sense, that for Sam is rooted in his own familial experience of having been raised by, and still living with, his birth family) and his own puzzlement as to why *David* has been forsaken by them. By contrast, Bob asks: "Where are the group home staff?" They despair the absence of friends and family in *David's* life, an absence made plain by the absence of these same people in the image. The trace of these absent carers haunts them and, incredulous, they wonder "how can this be?" If no friends or family, then surely there must be, at the very least, staff! How is it possible that he has been forsworn by everyone! When, in another meeting, I share with them the caption of the image, "David means beloved", this despair and incredulity is magnified.

As is clear from this and other points made throughout his work with the 'David' image, Bob seems strongly and determinedly focused on 'David' being institutionalized – the outcome of which is that staff, as opposed to family, are assigned to meeting his needs. I'm not quite sure why he holds so firmly to this opinion as it seems removed from his own experience. From our subway conversations, I learn Bob was raised by his birth family (although his mother died when he was young; he enjoys regular contact with his (aging and ill) father with whom he is close, and with his brother; that he sees little of his step-siblings and their children (though he speaks fondly of the children); and he is only member of his family labelled intellectually disabled. He has never lived in a group home or an institution. I am reminded that his girlfriend, however, lived (and died) in a group home. Is this the explanation for the tenacity of his interpretation? I do not feel that I am able to ask him this.

In this listing of responsible persons, a hierarchy of carers emerges with God at the apex, followed by family, friends and guardians, and, lastly, group home staff. Donna and Sam, again, credit families and friends as those who (should) care *about* people with disabilities, however,

Bob's and Donna's unshakeable emphases on group home and institutional care providers (staff who *don't* care about people with disabilities) reveals this idealized hierarchy as little more than wishful thinking – for the group (Sam being the possible exception), too many people with disabilities continue to be dependant upon institutional service providers. Spurned by natural carers (such as families and friends), they are not always cared *for* by people who would, typically, care *about* them. Consequently, they are too often cared *for* by people who care very little *about* them.

Carefully (Un)Covering Intellectual Disability

Sam: I just don't know why that the picture would have to look like this, uh, why the person who's disabled would sit outside all day by himself in the middle of nowhere, and he doesn't have weight and he doesn't have strength and he's very thin and he's bony, yeah, and he's wearing a diaper as well, and he's not eating enough.

Remaining, for the time being, with the image of *David*, Sam expresses two things with this fragment, both seeming to play on the double meaning of 'cover'. He reveals, again, his unwavering conviction that *David* has been left exposed and unprotected. *David* is physically uncovered, naked except for the diaper that he wears – a feature of the image that Sam cannot let go of. But *David* is also susceptible to the (mis)treatment of the photographer. With anger and a tired resignation, Sam questions the motivation for the making and publication of this image. Why this image? Why was *David* photographed *like this*? Why was this considered necessary? The image is a deliberate and particular kind of coverage of disability – a “bad story” - the believability and veracity of which Sam doubts.

Sam: Well, this honestly tells a bad story about people with disabilities, it is very bad....Also, it doesn't make a point, either.

Although (because?) he has been stripped down to the skin and bones of his being, Sam refuses to believe this image tells us anything truthful about *David*.



Whereas *David* is largely unclothed, the little girl in the *Blatt* image is, by contrast, covered to excess: the group remark upon the straightjacket and the cloth around her neck - neither being a protective nor caring covering – as well as the black band across her eyes. Physically, she is largely hidden from the viewer and they find it difficult to learn about the girl as a result.

Sam: Yeah, let me see [taking the image from Donna, he holds it to his face and looks at it very carefully and closely]. She's blind is she?

Ann: No, you know what? They covered up her eyes, um...

Bob: Right.

Ann: ...so that people wouldn't know who she was...

Bob: Right,

Ann: ...you know how they do that sometimes on TV if they don't want you to know who it's about? They'll kind of block out their eyes or their face or something?

Sam: Yeah, I mean they block out their face or their eyes I mean, maybe 'cause something kind of serious or private is kind of like on her eyes and they're kind of protecting it, maybe because her eyes is hurt or something, she's like bruised or black eyes or whatever.

In this fragment, Sam extends the thread of my explanation for the black band across the girl's eyes, undoing the erasure accomplished by the band. For Sam, covering her eyes also succeeds in blocking out “something kind of serious or private”, some knowledge the non-disabled carers want to protect or keep secret - the black band on her eyes veils the girl and, simultaneously,

hides even more abusive treatment. Again, the ‘truth’ is not given to the viewer.

What is emerging from the group’s work with this image are the conflicts inherent in their own understandings; both of ‘care’ and of visual representation of intellectual disability. On the one hand, they share the belief that the purpose or function of a newspaper image is to ‘educate’, to inform the viewer/reader about, in this case, disability – the reality or truth of disability. In one of our preparatory meetings, prior to direct work with the photographs, Donna, Bob, Sam and Robin articulate that newspapers are expected and have a responsibility to both ‘cover’ the story and to ‘un-cover’ (Wagner, 2000) the truth (and lies) about disability and, from this vantage point, they see some small value in the image of *David*: it is critical that newspapers include stories that make visible the lives of people with disabilities. Linking education to care (and simultaneously expressing her own caring for the people in the images), Donna confidently declares the public presence of the image is, in this regard, good because:

I like to learn about other people with disabilities, because I care about them!

Similarly, the worth of the *Blatt* image is its revelation of what is done to people with intellectual disabilities (even though what is revealed remains partial), how, as Donna states, it “tells non-disabled people not to make fun of people with disabilities”. Sam emotionally concurs, suggesting only “people with cold hearts would make fun of people with disabilities if they saw this.” Donna, like the others, stresses the importance and necessity of educating the non-disabled about “the true meaning of disability”, about what persons with disabilities can *do* and also what they do and do not *need*. For Donna, some responsibility for this task falls to labelled people themselves who, from her perspective, have an obligation to answer questions asked by non-disabled people when the questions reflect a genuine desire to learn – *if*, however, the asker is

disingenuous, is teasing or “being mean”, the obligation is forfeited. In the midst of this discussion, taking place during their work with the ‘David’ image, Bob turns to me and asks, “What would you do if someone asked you why [my daughter] Frances was disabled – would you answer them?” What follows is an expression of their own vulnerability in a brief but emotional sharing of their painful experiences of being (far too frequently) asked what was “wrong” with them, and the various strategies they have developed to handle the asking of these questions in ways that lets them protect and take care of themselves.

Much of the responsibility for teaching the non-disabled about disability, however, is assigned by the group to the media and, when considering the *David* image, they feel that the media has failed to exercise this responsibility in a manner that does justice to the man in the image. Bob understands the image to portray *David* as being locked away, in the dark. All four of them further remark upon the dark tones of the black and white image and they frequently hold the image close to their faces, seeming to strain to see what is held within it. As noted, Sam fears it makes *David* look as if he is being buried alive. In either case, *David* cannot be easily seen. Consequently, they feel unable to learn much about him. For Bob, the newspaper image of *David* is only a partial story, a fragment: “It doesn’t tell the whole story.” I tell the group that this was intentional and acknowledged by the photographer (personal correspondence, D. Campion, Feb. 28, 2007). Addressing, quite specifically and deliberately, the non-disabled viewer, Campion wishes to make plain the high level of care that he and *David’s* family understands *David* to need, and the consequent demands for such placed upon them, as his caregivers. The accompanying text and additional images elaborate upon such. The image is intended to capture a particular ‘reality’ – the reality of *David’s* body and what it entails. For Campion, it is not only *David’s* story (this being the smallest part of the story), it is also that of

his family. More importantly, it is the story of the photographer himself – his experience of *David's* body. Bob, Sam, Robin and Donna are, admittedly, cognizant of the ‘truth’ of the vulnerability and need for care emblazoned in *this* image of *this* man – they see the same things (although they are troubled by the photographer’s choice of image to portray this reality). Yet they are also recognizing how what they ‘see’ has been, at least in part, crafted, determined by the photographer and, as a result, they also question why so many public photographic images of people with intellectual disabilities show only those whose disabilities are more severe (like the image of *David*), persons whose dependence on others is (almost?) total. Discerning that this group of people is, in actuality, a minority within a very heterogeneous disability community – most of them do not even know anyone with an impairment like *David's* – they struggle to identify with *David* as representative of ‘persons with intellectual disabilities’. They perceive a disconnect between *David* and themselves: his experience only marginally reflects their experience of disability. For example, Robin, who has seen in his neighbourhood someone who is “a bit like this, a little bit disabled”, perceives *David* to be far more disabled than himself, *David's* disability “needs to be worked on” more than does his. Being independent is important to each group member. As a consequence, they worry that such images, as partial truths, convey an incomplete and inadequate picture of the (in)dependence of persons with intellectual disabilities and make it difficult for people without disabilities to come to know them (the group members specifically and people with intellectual disabilities more broadly), and to know what they need, more generally. In this manner, their lives are made (even more?) precarious.

Sam: Well, they would just kind of think that, um, that, that it’s kind of a little bit challenging to understand other people’s, um, points of views or other abilities, or, for example, um, even they would, uh, also say, um, that the person is, has like some kind of like different personality or something.

Robin: That he can’t think, can’t understand what’s going on. He has mentally challenges and he has a different personality and things like that.

They worry that the non-disabled (or differently disabled) viewer is led by the image to regard all people with intellectual impairments as being the ‘same’, being like *David* and needing the same types of care that *David* needs, because this is what is inscribed in the image. For the group, the connection between visual re-presentation and care is clear – it is vitally important that, through caring and care-ful visual re-presentations, people without disabilities come to more fully know about the heterogeneity of persons with intellectual disabilities to ensure that they are treated well, that the ‘care’ that is provided is the care that is required. In the case of the *David* image, Robin concludes that it is because non-disabled people don’t know *David* that they have abandoned him and left him alone. Ignorance of disability is implicated in their own experiences of oppressive and violent care, of being teased, ridiculed, hurt and rejected.

Robin: It [the image] doesn’t, it does not explain it [intellectual and developmental disability]. It just tells you the picture is sad.

And, later in the conversation, Donna (who is visibly distressed) says:

I don’t like it when people make fun of me, especially on the street, calling me names, oh my God! ...There’s a lot of ignorant people in this world.

(Un)covering intellectual disability: Picturing care differently.

Before going further with Bob, Sam, Donna and Robin’s critique of the *David* image, let me weave into this discussion the group’s work with a third image. I do so as this work also speaks directly to questions of vulnerability, dependence, meanings of care and to uncovering what (some) people with intellectual disabilities (do or are constructed to) need. The image was also necessary to their fleshing out of *David’s* story.



Ann: OK, alright, what do you think Donna? What do you think this picture is about? (there is a pause while I wait for Donna to answer). When you look at this, what do you think the picture's about?

Donna: It's about (pause), its about, like, that she has a disability and, uh, um, um, a disability and uh, um, (pause) this just reminds me that she can't walk and she can't feed herself...

Sam: Yeah, that's exactly what I was going to say!

Donna: ...and she can't even go to the washroom herself, so...and she can't wash herself.

Ann: So she needs a lot of help?

Donna: Yeah, she needs *a lot* of help!

Ann: What does the picture tell you about people with disabilities?

Sam: Well, just people that have special needs and who just, uh, also what they are capable of and what they need and what they, um, also um, just uh, what, what their personality is like.

Ann: OK, what kind of 'personality' do you think this person, the picture shows us this girl has?

Sam: Um, the kind of personality that this girl has here, shows that, uh, that [she needs] some kind of a person who's capable to take care of someone who has issues that can't take care of themselves, [someone who] needs some kind of a person who, um, a guidance assistant.

Ann: She needs someone to take care of her? A 'guidance assistant'?

Sam: Yeah.

At another meeting, I ask Bob:

Bob, what do you see when you look at the picture?

Staring intently at the image, studying it carefully and completely as he turns it over, touches it, and points to different things in the image, Bob seems to look to me for confirmation of his interpretation. He tells me:

I feel sad, inside, because the person just can't function like you can, like normal, can't function as normally as you can, she has to be in a wheelchair and cared for all the time. Some people, some disabilities are like that...

As they did with the image of *David*, Donna, Sam, Bob and Robin understand the subject of the image, *Tracy*, to be vulnerable and in need of care, evincing her body, her physical impairment, and the very large and pronounced wheelchair as markers of this need. Reminiscent of their assessment of *David* and of the child in *Blatt*, what is evident to Bob is *Tracy's* unhappiness. Pointing to her face, in the spotlight created by the table lamp directly above her, he notes:

Bob: And she's not smiling very much in this picture.

Ann: And that strikes you? What do you think that means?

Bob: That means she's sad, that's right, that's another thing [that strikes him].

In their expressions of concern for the girl's safety and comfort, their attention to the (uncomfortable) positioning of her body in the image, they subtly berate and challenge the photographer's/editor's decision to create and publish *this* photograph. Dismantling the image's construction, they note the pieces of equipment encumbering the scene, encumbrances that serve as additional markers of the need for care.

Bob: Or she might be in some kind of a group home – that's one thing I was going to say. In a group home, where they have some kind of special setting for her, a special bed, and she can't lay down [in a typical bed] – she needs a bed that's more comfortable for her, and then she needs a wheelchair that's more easy for her back, I'd say, so she can function better.

They remark frequently on the staging of the image: the bed behind the seated woman and girl; the room – variably understood as representative of a hospital, a hotel, a group home, or a wheelchair accessible apartment.

Sam: Yeah, like is this some kind of, are they in some kinda apartment or is this some kind of, like, like a, like, I don't even recall if this is like a hospital but, no, that's not a hospital because that doesn't look like an emergency clinic or whatever, and uh, I would not even recall this is a, that this is a hotel or anything

but, I think this is just, oh, I think I know what this is! I think this is some kind of, what's it called, some kind of like a disability home but, like some kind of a resident group home!

As a signifier of disability – “visual shorthand” (Barnaby, 2005:1) – it is, however, the wheelchair that most strongly arrests their attention. Consuming half of the image, the wheelchair has been foreground; a large, mechanical presence. Many times, over the course of the project, they voice their belief that the mere presence of a wheelchair in a photograph tells you the person is disabled and, more so, that this is what it is intended to do.

Sam: Yeah, well the reason why it [the wheelchair] is big because, uh, there is something wrong with the girl's body, like she has some kind of a pain on one of her body part, like maybe something on her upper hip or maybe because on her bottom or legs, or even especially relating to her feet or anything.

Ann: So you think they put it there to remind people that she has something wrong with her?

Sam: That, that, well, yeah....

And later:

Donna: Um, it just reminds me that she can't, she can't walk and she can't do a lot of stuff on her own and, um, she's got a disability...that, that's what it reminds me of.

And later:

Ann: So, that's the first thing they want the picture to say? Is that this girl's disabled?

Bob: Right.



Far from being a neutral imaging, the wheelchair is what defines the girl and, in emphasizing what she cannot do, conveys the ‘fact’ that she is impaired, dependent, un-able – she needs others to provide care, to do *for* her. This is the message they, without hesitation, believe the newspaper wanted to stress and what the newspaper determined the photograph would ‘say’. It explains the rest of the image to the viewer. This is not a personal photograph of this young girl, a photograph that tells us about her, about who she is as a person, or about her life outside of this room. Instead, it has been framed in such a way as to tell us only what she cannot do and, in so doing, to inform viewers what *others* must do for her. This blatantly reductive and excessively staged representation is problematic for Bob, Sam, Robin and Donna who struggle with the fact that, in this image, “you see more of the wheelchair than you do see the people” and the overabundance of such images: “[t]his is not the only time that I seen a picture like this!” They

are acutely aware that images, the visual ways in which the stories about people with intellectual disabilities are told, have the power to hurt. As Robin observed in his work with the *David* image, the photograph does not tell the whole story, it does not explain intellectual disability. For the group, the sheer size of the wheelchair, its prominence in the image, works to delimit the girl to her physical dependence and, as a mechanism for such reduction, it hurts:

Donna: Yeah, I find that very strange, that's, that's, you know, I mean if you're going to show a picture of somebody, at least they could put it aside or something, like put it out of the way of the picture, you know what I mean?

Sam: So people can see the picture and not so much the wheelchair.

Donna: If, like, because I think that looks, uh, I don't know, to me it just looks ridiculous.

Ann: Yeah?

Donna: I mean, if it's anything, it should be the mother and the daughter in the picture and just move the wheelchair out of the way, out of the picture, you know, you have this big thing here, I mean, like, this does not make any sense.

Sam: Oh, yeah.

Donna: I find it confusing, to tell you the honest truth, you know.

Sam: Yeah, that's true.

And later,

Sam: I think he should'a, really, took a picture of *them* [the woman and the girl] and not so much the wheelchair!

And, at another meeting,

Bob: I agree, make them hurt, I agree with what him, it can make them hurt. 'Cause this is not right, to make them hurt, that's my opinion.

Interestingly, Donna and Sam go on to trouble this (their own) seemingly straightforward critique by offering up a very practical counter (or additional?) explanation for the type of inclusion the wheelchair is accorded in the image – an explanation that serves to humanize both the girl and the concerned viewer:

Donna: “I guess to make it accessible, to get her out of the wheelchair and put her back in the wheelchair. To make it easy so that they, if they have it too far away then that means she, she has to get up and walk over and get the wheelchair and bring it over. So maybe she didn’t want to go, maybe she didn’t want to have to walk too far, maybe that’s why it, it was put there. You know what I mean? Like sometimes people don’t want to have to walk too far.”

The presence of the wheelchair triggers Donna to speak of her grandmother who is 102 years old, quite frail and living in a nursing home. Donna treasures her visits with her grandmother and laments the distance between them – a distance Donna cannot travel alone, nor afford to travel very often. Like ‘Tracy’, her grandmother uses a wheelchair and Donna speaks often and with great distress of the attention that must be paid to her grandmother’s fragile body and delicate skin, the care required to transfer her in and out of her wheelchair without causing harm. Her own attention to this, reflected in her reading of this image, serve as an unintended chastisement to my own reading: seeing only a dysfunctional representation, Donna unknowingly reminds me that I have ignored my own intimate knowledge, my own remembrances of seating my eldest daughter (and others I have cared for and about) in wheelchairs.

Sam: Well, it would be fine if they had to put, to show the wheelchair because, uh, the wheelchair in the picture, so for the girl who had physical intellectual disabilities or something, because, so if, um, it was without the wheelchair in the picture and they just, uh, showed without it or something, um, then they [the viewer] would think, “OK, well if that person is kind of like, if the person looks like she looks...”, and other people, they look at it and they think, “Why is this person crippled?” and, “Why is she that or so?”, um, “Is there any other way to prevent, to put, um, put her in a, like, into some kind of a special seat to, kind of like, support her body so it doesn’t, um, get too hypergetic or so?”

Ann: OK

Sam: Yeah, ‘cause they wouldn’t think this would be safety without the chair.

Ann: Oh, so you think that maybe if people didn’t see the wheelchair they would wonder about the girl’s safety?

Sam: Yes.

Ann: Ah, OK. So they would wonder why she was being held like that?

Sam: Yeah, they would think that this would be, like, odd or strange or something.

Ann: OK, OK, I hadn’t thought of that one!

With anxious voices, and frequently looking to the other for support, Sam and Donna are drawn to and visibly upset by what they seem to regard as *Tracy’s* very real, but overwhelming, care needs and the manner in which these have been portrayed in this image. They search for, and find, alternative explanations – more acceptable, insider, explanations – for what they see. As

we continue to talk about the image, over the course of several meetings, a consensus emerges within the group: the wheelchair *is* necessary to the telling of (one of) the girl's story/stories *and* this story should be told in the newspaper *but* the story must be told in a different way.

Donna:(pause) um, I guess, basically, that' just letting people know what, [people] that don't have disabilities, to know what it's like to have a disability and not to, not to run them down or call them names..."

Ann: OK.

Donna:...so, they, they're trying to get them, uh, these people here are trying to get, that's why they put it in the newspaper, to get the word out to people that don't have disabilities and um, to, to, to think, to think, um (pause) to know what's it like to have a disability or be born with a disability...

Ann: OK.

Donna:...that's why I think, this is why it was put in the paper...

Ann: OK.

Donna:...that's my opinion.

It is at this point that I furnish them with the caption for the image. Consequent to their discussions, their interpretations of the image, they do not believe the caption to be appropriate to the image – it does not tell viewers/readers what they feel should be told.



In this, their first re-telling or re-imagining of *Tracy's* story, of one meaning of care this image provokes for them, they choose (in some ways reminiscent of the photographer of the original image) to concentrate upon the girl's physical vulnerability, her dependence and need for

support. Citing the insufficiency of the original image (a function both of the omission of certain details and the obfuscation of others as a result of the dark tones, the amount of space taken up by the wheelchair, and the positioning of the bed behind the wheelchair and the people), they elect to provide concrete information (examples of the types of support she requires) and more of it and to construct the image around this. Their reference point for this decision is located in their personal experience as ‘clients’ of developmental services agencies and familiarity with corporate media; with billboards, for example, which they (trusting) understand to function as conduits of (accurate) information to the rest of the world about disability^{xvi}. They talk, quite excitedly, about service-agency billboards, extolling their positive effects on non-disabled viewers and on the disabled subjects whose images adorn them.

Bob: But each picture tells a story, just like these, but there’s [images on service agency billboards] more detail.

Holding tightly to the image, waving it in the air and emphatically pointing to it as he expresses his thoughts, Bob eagerly shares his opinions as to what should be included in their transformation of the image:

I want to find out if there’s any, uh, any staff looking out for her everyday. I want to find out. Like we’re different people than what they are because we’re in the apartment program, but we still have counsellors, right, looking after us, but they have to have different, special needs, ‘cause they’re special kids, what they call special needs, that’s right, to help them out. If you need special WC’s, you have to, if you need special clothes – like diapers or something, they can’t get to the washroom, something like that, that’s right.

To counter the limits of the original image, the group tells me they want to include information about where she lives and how accessible it should be; the availability of support persons; necessary equipment; and financial support. They want to know, and the viewer to know, more about what her daily life is like. They label these things to emphasize and make plain what they

feel is important for the non-disabled viewer to know. Sam makes the additional point that it is important to show that the people who provide this support are doing what they have been charged and entrusted to do:

Sam: Well, because it describes, um, something what's obviously, um, like this, what this is honestly talking about and also about what the person who has disability, what they, uh, need help with and then, the person who's taking care of the, uh, person, um, who has a issue, to, um like who has some kind of a mental problem or so is, um, doing her job and, uh, and, and absolutely is doing the right thing what she has to do for her.

As they did in their work with *David*, they repeatedly stress the value of knowledge of disability, knowledge of people with intellectual disabilities, as a means of breaking down intolerance. But I am initially troubled by this service-based rendering, this (to my eyes) rather pedantic re-imagining that seems to swallow the person who, I feel, should be at its heart – for me, she has become lost amidst the itemized supports. With its mechanistic interpretation of ‘care’, this reconstruction has such a ‘rehab’ feel to it. Silencing my discomfiture, I ask for explanations – why *this* change? The group members state the inclusion of more information will enable the viewer to learn about *Tracy's* life and what she needs. The (original and transformed) picture's emphasis on *Tracy's* body provides enough information about her impairment – what is required is more detail as to the supports that should be in place: “how is the picture going to actually tell the story if you don't actually see everything that's in the picture properly?” Asserting that “the story is *there*” but the image cannot tell the “right” story without including enough information (information about what *Tracy*, herself, would say is needed) and presenting it as clearly as possible - doing it “properly” – they proffer this as the means by which to educate non-disabled people in a way that cares for people with disabilities.

Further, while the group does, quite often, highlight *Tracy's* dependence, they appear to simultaneously attribute to her agency, disrupting the dependency relationship between the young girl and her caregiver in the original image. While often highlighting their own determinations as to just what *Tracy* needs, frequently their comments are rooted in *Tracy's* perspective, or, in their suppositions as to *Tracy's* preferences: '*Tracy* would/wouldn't want...', 'she would/wouldn't like', etc., thus foregrounding *Tracy* over the supports and indicative (perhaps?) of their concern that her choices be honoured. Donna, Sam, Bob and Robin observe that they are all physically more able than the young girl in this image – they do not speak to their thoughts about her cognitive ability. I am not sure if they are attributing to her the cognitive ability to direct her own supports or, in acknowledging the severity of her impairments, they are speaking, not so much *for* her as, from their shared position as people labelled intellectually disabled – from a knowing rooted in this position – with her or even *as* her. Either way, they make *Tracy* present, and I begin to see how, for them, their transformation of the image reflects their caring: the image itself is, in their estimation, "better"; a more care-ful one that no longer hurts *Tracy* or other people with intellectual disabilities. The image corrects the physical hurt they presume has been done to the girl through the awkward positioning of her body – they have seated her in a more upright position. More than this, however, it makes room (as well as a more suitable 'room') for *Tracy*, for this person's differences, inviting new understandings. In their minds, it will lead to better care – now that the viewer can see and thus know what people living with *Tracy's* type of impairment need and have the right to receive, they will be provoked to action and will "try to do something about it". By putting the "right" story in the newspaper, they create an opening to effect change. Steeped in hope, they trust that, with knowledge, people will do the right thing.

Good Care = A Caring Touch

Sam: What I see over here, is that, um, that the lady who is sitting on the couch is carrying the person who's in the wheelchair, um, in her lap, or so, uh, maybe like, um, just like carrying her by, um, just in her lap...just a hold like maybe like a hug, just like carrying, like some kind of...not a hug carry but maybe like sitting on her lap like a little, like some kind of, like a child, just like for a little close company, or, like, to be, like, loving or caring or whatever.

Audible in much of the group's discussion of the *Tracy* image, was the notion that something good was contained within it – difficult to articulate but nonetheless present. Working to understand what he sees in the photograph, it is Sam who first lights upon the woman carrying or holding the girl in a manner suggesting a “hug”; the girl sitting on the woman's lap “for a little close company”, for “loving or caring”. The result is the emergence of a second, quite different, interpretation of ‘care’ and the visual representations and storying of such: this second interpretation, exemplifying the group's affective concern for caring *about*, for care as love and loving care, is hinted at in the more pragmatic first visual response.



In this first transformation, Bob, Donna, Sam and Robin identify ‘love’ as something *Tracy* needs. Love is understood as a form of support and the word itself is placed near the woman's hands wrapped around the girl's waist; it is set upon the girl's heart. But Sam was somewhat more dogged than the others in bringing attention back to this question of love:

Sam: Yeah, I mean, or maybe as a matter of fact, she just had to sit down for awhile, just to, kind of comfort her and keep her company or something.

And later,

Ann: “What is the picture about? What do you think about when you look at it?”

Sam: What I obviously think of it, uh, um, it’s obviously a, a, what’s it called, a fine OK picture or so, but um, and it just, I would say that it tells that, uh, um, that the woman is honestly trying to, to um, like the reason why she’s holding her in her lap again, once again I was gonna say, is that maybe she’s just um, just taking care of her and just, uh, keeping her at a warm side or so.

Ann: Uh, huh.

Sam: Trying to hold her warm and safe.

Ann: OK, so when you say ‘warm’, are you thinking temperature warm - because she’s cold? Or are you thinking ‘warm’ as in, sort of ‘loving’ warm?

Sam: Well, just as a loving warm (pause) and also giving the girl care as well.

And later,

Sam: Yeah, loving care and also support and the support that they need is what I meant to say (laughs). I, I almost forgot that, that, forgot these words, like sometimes, sometimes when I’m trying to talk and when I’m trying to get at a point, it, uh, it’s so crazy and I, like, I lose my words.

It is this persistence that calls for a second visual response to the *Tracy* image – one which Sam initially struggles with articulating but is then determined by the group, together.

Ann: Right. So how would we change this picture [*Tracy*] then to show everybody that what’s important is the fact the girl is being held? How would we change the picture?

Sam: Uh, how we would obviously would change the picture is by, maybe, um, if, if, if the girl in the wheelchair was maybe like, uh, being like held, um, by, like not, not in the lady’s arms or something like that, but maybe, perhaps, um, if she had to be, um, I don’t know if you put this, put her on, put her into a bed or something, but maybe if some kind of another person would help her out to, uh, to give her, um, the support and the, and also the caring of needs about, um, maybe like giving her some kind of like, um, freedom out of the wheelchair for a break ‘cause if she’s been sitting in the wheelchair?

Ann: But, but what you guys said was that what was important was that the girl was being held and that this shows caring and love, right?

Sam: Yeah.

Ann: So, if we put her in the bed, does that still show caring and love in the same way?

Robin: No.

Bob: No.

Sam: No, it doesn’t.

Ann: So, if we want to make sure that when people look at this picture the important part is this part [the holding], what could we do to the picture so that they know the important part is being held and being loved and being cared for? How can we change the picture so they know that? What can we do?

Sam: Well, um...[Sam looks to be thinking hard here, concentrating yet unsure of what to suggest – Bob, meanwhile, is watching Sam, awaiting his answer.]

Ann: Donna, you got any ideas?

Donna: Um, how could we change it, um, ...um, well, my opinion, I don't know about anybody else's opinion, I wouldn't want, um, no, I just don't like the picture the way it is, I don't think I would want the wheelchair in there because...

(extended pause).

Ann: So, if we take the wheelchair out, if we get Ted to take the wheelchair out, then do people know that what's important is the fact that she's being held and cared for?

Donna: Well, that's my opinion, yeah, but I don't know about anybody else's.

Ann: Is there any other way that we can show that?

Sam: Um, well, maybe, um, as a matter of fact, yeah, that should be the best way how to do it, as long as, uh, the lady knows how to carry her properly, then of course, that shows us that she's being...

Ann: Does that mean that we need to change her posture, change the way she is? [In an earlier meeting they had discussed their concerns over the girl's posture, the risks this posed to carrying or holding her, and their desire to show the girl in a more upright position.]

Sam: Yeah, change her posture...

Ann: OK, so what...

Sam: ...'cause if she had a poor, improper posture or something then maybe it shows that she doesn't like being held up or anything.

Donna: Well, put her straight up.

Ann: OK.

Donna: Put her sitting up, sitting up like this [demonstrating sitting upright], we're sitting up like this right now, put her straight up like this!

And later,

Ann: What about you, Bob?

Bob: [pause]...I don't like the picture 'cause its the way it is

Ann: The way it is? Because of what part? The posture? Is that what you meant?

Bob: Yes, yes, she should be sitting up straight [gestures sitting up straight], instead of bent like this [bending over and pointing to back] – it hurts her back.

Ann: So, you don't like the way they show the girl?

Bob: Should be better posture, that's what I'd like.

Ann: You don't, you don't like the way that she's holding the girl?

Bob: Right.

Robin: [I cannot understand first few words he says] over her ribs, she can't hold on, she's hanging on, like she could fall, you don't know what's going to happen to her...

Ann: Right, right, and you thought she was going to smack her head, right?

Robin: Yeah, yeah, smack her head, like, instant.

Ann: OK, OK, alright, um, OK.

Sam: And she might happen to, like, crack her head open, or her neck might break or something which that's something I don't even want to [holds hands up as

if to ward this thought away]. I'm so afraid to say these kinds of things or something, but...

Ann: No, that's OK.

Sam: ...that's why I wouldn't have to like bring something, like so depressing and very harsh in, you know...

Ann: Right, right.

Sam: ...and very disappointing I mean.

Ann: That's alright.

Sam: Yeah.

Ann: But that's the whole idea here – that you say what you're feeling, right?

Bob: Right.

Sam: And she could also break bones, break her bones as well, she could be dead!

Ann: You're right, you're right.

Sam: She's very weak and sensitive and she may have like a low blood self esteem.

And later,

Sam: Um, the way how the lady's holding it is not in a proper way, 'cause, uh, 'cause the girl in the wheelchair is not in a proper, um, posture, and it doesn't look very nice and it's not good for her and it's very honestly, uh, uncomfortable for her to be feeling, to be in that position, and it makes other people feel uncomfortable and it bothers, it's really a lot of a bothersness to them.

Their words reveal, again, their distinction between 'caring for' and 'caring about'. Altering the image in such a way as to portray *Tracy* lying on the bed might suffice as a means of demonstrating caring for her physical need to have a break from sitting in a wheelchair, but is insufficient to articulate the loving and protective relationship captured by the woman's arms wrapped around *Tracy* – the love and protection they want *Tracy* (and themselves) to receive. It is this holding that is paramount and is accomplished, first, by removing the wheelchair – the marker of impairment dominating the scene – and by highlighting, or 'making bigger', the touch. Speaking of her as if she were real and in immediate danger, their own caring about *Tracy* is apparent in Bob, Sam and Robin's concern for her safety. Bob, for the most part, has been listening to the others, pointing to them and encouraging them to talk. Asked for his opinion, he is suddenly full of movement, rubbing his head and eyes, shifting in his seat, looking at each of the others as he asserts his dislike of the image. He proffers his opinion *Tracy's* position might

be uncomfortable, might hurt her back. Robin, from the onset, has worried over the threat posed to *Tracy* by her posture and returns to it here, anxiously worrying that, unless she is repositioned, *Tracy* will “smack her head”. It is Sam, however, who becomes increasingly fearful – his voice rises, he looks more and more anxious – and smacking her head escalates into something worse as he envisions *Tracy* as cracking her head open; breaking her neck; breaking bones; and being killed^{xvii}. *Tracy’s* well-being, her very life, depends upon being seated properly and being held safely – on being kept safe. Tracy concerns them and, to some degree, she has become their responsibility – a responsibility to be enacted in a re-imagining of the holding that already exists in the image. Reflecting this in a transformation of the image necessitates we attend to the girl’s posture and to the woman’s hands holding the girl, to highlight this holding and to modify the image to ensure it is clear that this holding is a caring hold, a safe hold; to focus “on the grip, like make sure it’s tight”. They tell me that if someone *really* loved her, they would hold her properly and keep her safe – with love comes (un-refusable) responsibility and accountability. They instruct me, too, to take the girl and woman out of the less pleasurable clinical scene and to place them in a “nicer” place, like a park, where they could “sit on a bench” and “enjoy the day”.



Following on the heels of their work with the *Tracy* image, the group eagerly selects four of a series of images produced by the retailer, *Benetton*, for their *Sunflowers* advertising campaign, to work with. As Sam notes, these photographs are “easy to talk about, the other one was hard to

talk about; the ones from the past were hard to talk about.” They are easier because they are easier to understand – at their most basic level, the images are about “happy people”. Free of the complications and complexity they saw in the other images, they spend comparatively little time with these ones.

Donna: ‘Cause everybody likes the way they are [Benetton images], you know? I like happy people. I don’t like pictures that go...like that [Tracy image] and not happy or not smiling, you know. I want happy people. I don’t want sad people and, you know...

Sam: And depressing people.

Donna: ...yeah, well, you know, I’m tired of looking at depressing people...

Sam: Me too, and I feel very terrible about all this.

Two of the *Benetton* images, in particular, resonated for their similarity *and* difference to the original *Tracy* image and their second transformation of it. Here is the first:



Ann: What do you think it shows then?

Donna: It shows love, see, it, the mother is, it shows the mother is loving her, see, holding her and stuff like that...

Bob: Right.

Donna: ...you know, holding her close.

Sam: Yeah, that’s what it shows, love.

With relaxed bodies and faces, Sam, Bob, and Donna smile as they gently touch this photograph with their hands and eyes. Questioning whether the child is a girl or boy, and whether the woman is the child’s mother, nanny, or babysitter, they nonetheless quickly decide upon the

story of a mother lovingly holding her son in her arms at the park – a story which, from the tone of Donna’s voice and the looks she gives me, I should have recognized as being obvious.

Returning, then, to their concern over the posture of the young girl in the *Tracy* photograph and its effects on the woman’s ability to safely hold her, Sam points to how this image differs:

Sam: Yeah, this (mother and son) is almost like the girl in the wheelchair, a little bit but, um, but um, problem there is a difference between the other picture and also this...

Ann: What’s the difference?

Sam: ...she’s holding the boy, um, properly...

Ann: Hmm

Sam: ...but um the one with the other picture of the girl in the wheelchair, the lady wasn’t really holding her very properly.

While this child in this image (like the subjects of the *David* and the *Tracy* images) has a more severe impairment than do any of the group members, they do not worry over this child’s safety. This child’s mother is concerned, is responsible, and is keeping her child safe. Nor are they disturbed by how the child’s impairment has been visually represented. Emphatically pointing to the *Tracy* image on a table across the room as she speaks, Donna goes on to say:

Donna: At least you don’t see, you don’t see the wheelchair or anything in the way.

Ann: Right.

Sam: That’s right, that’s honestly more professional [*Benetton* mother and child], the other one was very unprofessional [*Tracy*] and not practical but that’s more practical you know...

Donna: Yeah, ‘cause you don’t see the wheelchair and you don’t see anything, you don’t see her wearing the slippers or anything, you don’t see any of that, and you don’t see her going like this [gesturing the splaying out of the young girl’s body], so this is a good picture [*Benetton* mother and son], I like this one, this is a good choice that we made.

Ann: Okay, you like that one better [*Benetton* mother and son], OK.

Donna: Sorry, it’s not trying to insult anybody.

And later,

Donna: It shows love, see, it, the mother is, it shows the mother is loving her, see, holding her and stuff like that...

Bob: Right.

Donna: ...you know, holding her close.

Sam: Yeah, that's what it shows, love.

The absence of all that they disliked about the original *Tracy* image is what makes this image of the mother and son so appealing, so much “better”. The image does not “insult” anyone – neither people with or without disabilities. Instead, as Sam later says, it makes plain to the viewer that “people with disabilities like loving care”, and that “people without disabilities can love people with disabilities”. For the group, this image is simply an image about love. Because of this, the image does not call to them to be responsible to or for the child held within.

Absolved from this responsibility, they express neither the desire nor the need to change it, only to pair it with their second transformation of the *Tracy* image as, from their perspectives, both images tell the same story of love. Paired this way, the images assume the quality of photos in a family album, pieces of a family's story. Interestingly, Sam, Donna, Bob and Robin (prior to having seen the *Benetton* image) stage their re-construction of the *Tracy* image along eerily similar lines to those used by the photographer of the *Benetton* image: a natural park setting on a bright and sunny day, a child lovingly (and securely) held by an attentive (and responsible) caregiver – faces held close, the caregivers are smiling, gazing affectionately and directly at the child.



Below is the second image from the *Benetton* series that triggered comparison to the *Tracy* image and, also, to the *Benetton* image of the mother and son. It is, like these other images, a photograph of an adult with a child, apparently in a park on a sunny day. As the meeting started, only Sam, Donna, and Bob were present. Here is their first exchange about this image:



- Sam: This one's more perfect...
- Bob: That one's better.
- Sam: ...that one's perfect.
- Ann: Would you guys like to change this one at all?
- Sam: No.
- Ann: Is there anything about it?
- Sam: Er, it depends because, what's it called, maybe a little bit of a something, maybe about, a slight of a change, but the rest is absolutely perfect, but, uh, ...
- Ann: What would be your slight of a change?
- Sam: ...at the same time it's perfect, um... Well, the kid's head is kind of tilting, like, to the left, which kind'a looks...but if his head was straight up, then that would be perfect.
- Donna: Yeah, if you could put his head, the head straight up...
- Ann: OK, what do you think he's doing with his head here? What do you think that's about?
- Sam: I have nooooo idea!
- Donna: You think maybe he's going like this [titling her own head onto her shoulder] and resting his head on, on, on, on his shoulder?
- Bob: Maybe resting.
- Donna: Like some people do this (resting head on shoulder), like...
- Ann: Yes, or...yeah. Or do you think he wants to be touching his hand [the father's hand that rests on child's shoulder]? Do you think he wants to be close to his hand?
- Donna: Yeah.
- Sam: I would say that it could be that, maybe, yeah, something like this.
- Ann: Are you OK with that, or do you still think his head should be straight?

Sam: ...um, he's just resting his hand there and it doesn't matter 'cause his head's probably tired and he just wants to lean on it or just for a matter of fact, for, or a matter of fact that man just, uh, just decides to, what's it called, have his hand onto his shoulder to like kind'a keep the boy relaxing and just, uh, quiet and also, um, to, as well, um, make him feel that he's, um, honestly being touched by a warm sense.

Ann: OK, that it's like a warm hand or a warm feeling?

Sam: Well, just like a caring feeling...

Ann: A caring feeling?

Sam: ...yeah.

Ann: OK, I wondered what you would think because do you remember...

Sam: Just to make him feel better and cheer him up. That's what I think.

Ann: OK.

Sam: That's what I meant by that.

And later,

Sam: But, the same thing or something, but the thing is, that I was gonna say, um, is that, well it just shows that the boy is honestly being wanted by his elderly parent.

Ann: OK, so that it shows that he's wanted?

Sam:

Yeah.



Interjecting only occasionally, Donna was paying close attention to what Sam was saying.

Resting his head on his hand (in a manner reminiscent of the image itself), Bob quietly follows the conversation. Sam's interpretation of the image evolves as he spends time with the image and the discussion. His initial approval, "this one's more perfect", gives way to hesitation as he notices that the child's head is tilting to one side, "a little bit of a something" that isn't quite right. His uncertainty is in view and, as with the *Tracy* image, he is unable to explain why the child is/has been positioned in this way. Donna suggests the child may simply be resting.

Picking up on their discussions preceding this one, conversations about the importance of touch,

I raise the possibility this may be about seeking out the man's touch, a suggestion with which Donna readily agrees. Still struggling to make meaning of this aspect of the image, Sam is reluctant to commit to this immediately, yet, as he talks, this explanation appears to take hold: the child is resting against the father's hand, a hand that, first, is supportive – helping the child to relax – and then, through touch, conveys caring and, finally, love and acceptance. It is the touch of the father's hand that tells Sam (as the viewer), and the child (as the object of the touch) that the child is wanted.

Here, Robin enters – both the room and the discussion and, by doing so, immediately and powerfully disrupts what Sam, Donna and Bob have been reading in the image. Looking steadily at the photograph as the others watch and await his reaction, Robin points to the dark area of the image where the child's body and the man's leg meet, and tells me he is concerned about the little girl – she seems to be sitting on the man's leg and he is fearful she may fall. I suggest that maybe the man is using his leg to hold her in place; perhaps she has a physical impairment that would require this. But Robin clearly disagrees. He insists this is a question of her safety and her comfort:



Ann: You think it might be uncomfortable?

Sam: [seeming very surprised] Oh, *that* was the problem! We couldn't even see her clearly!

Robin: And how's she doing with her head is like this (leaning his head to the side in imitation of the girl's head in the photograph) – it's supposed to be straight up...

Ann: OK, yeah, everybody kind of wondered about her head.

Robin: ...and why is her head like that?

Sam: That's, yeah, that's the thing – oh my God, Robin noticed something! You're very smart about that, 'cause I couldn't even recognize what's all this [pointing to the dark area of the photo around the girl's torso and the man's leg], 'cause the whole thing is like black inside or so, I couldn't recognize the legs or anything. So yeah, that, that, that doesn't look very good you know, because that could obviously hurt the right man's leg and after the little kid's sitting on it, and it's very sore.

Robin: And he kicks her, like this (demonstrating kicking child off leg). He could hit her like that ...

Ann: Oh dear.

Robin: ...so she goes like this (demonstrating falling forward as if kicked)...

Ann: Oh dear.

Robin: ...that could happen, something like that!

Ann: Alright, so you're, you're afraid she's uncomfortable, right, or you think she might fall, or that the man might kick her?

Robin: Yeah, that's right, you know.

Ann: What, what, what about the man makes you think he might kick her?

Robin: Maybe, he might kick her.

Ann: So, do you think he might kick her on purpose or would it be an accident?

Robin: [shrugging] Maybe an accident, he didn't know...

Ann: OK.

Robin: ...he didn't realize that the girl was sitting on the bench, maybe he didn't know.

Ann: OK.

Robin: [I could not really hear what he said here but it sounded something like, 'taking the leg out'.]

Ann: So what would you change in there? You'd want to take his leg out from there?

Robin: Yes.

Ann: And you'd want her head up?

Robin: Yes.

Ann: Is there anything else you'd want, you'd want to change?

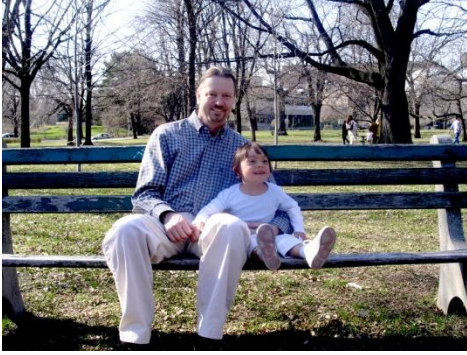
Robin: Just pull the leg out and the head straight up.



Robin sees danger and violence lurking in the image and, although it is somewhat obscured by darkness and shadow, the threat to this little girl (from her parent, the person most responsible for her welfare, and the one who should most care for her) is, for him, very real. The father's touch is not a good touch. His voice and words expressing surprise over Robin's alternative interpretation, Sam looks again at the photo. He, too, points to this dark area and seems to use this as explanation for the differing interpretations – he, Bob and Donna hadn't been able to properly 'see' what was there: “‘cause the whole thing is like black inside or so, I couldn't recognize the legs or anything.” Despite this, Sam does not yet see the danger that Robin does – his attention turns to what he supposes will be the man's discomfort. Perhaps picking up on this, Robin more forcefully makes his point – the man may kick the child, may hit her. Sam stays silent but Robin continues to press his point and, while he verbally appears to entertain my suggestion that this might be accidental, his shrugging of his shoulders and off-handed way of acknowledging this possibility, suggests he is not buying into this possibility at all. Later, he points not only to the man's leg touching the child, but also to the positioning of the man's hand on the child's shoulder – both of which he interprets as violent, dangerous touch. Robin comments, too, upon the man's direct gaze at the camera – a gaze he contrasts with that of the women in the previous *Benetton* image and in the group's second transformation of the *Tracy* image. Whereas the gaze of the women spoke to their attentiveness to the children, to a particular type of presencing, this man is not present for the child in the same way. His gaze is interpreted by the group to signify un-care, to add to the violence they read as being held within the image.



Once again, they feel summoned to take care of the child, to ensure her safety. The image needs to be changed, a different representation, a different storying is demanded. Led by Robin, the group initially wanted to use Photoshop to “fix” the positioning of the girl’s head and to remove the man’s leg from under her, however, a much different visual response emerged from their work with another image. Meeting at a park, the group had asked Ted to take digital photographs that they would direct as a means of responding to a charity image that they had worked on. This meeting proved to be a great deal of fun. The group attracted an audience (which included my partner and daughter) who watched with interest as the group talked with Ted and responded to his sharing of information regarding lighting, positioning, etc. Becoming more and more excited and actively involved as the meeting proceeded, it appeared to me that the process of talking about, posing for, and reviewing the images sparked the group’s creativity. They became more animated, more direct in the staging of the images. The result was the creation of two other images that connect to the notions of ‘care’ and ‘touch’. The first of these speaks directly to the *Benetton* image of the man and the child and, from Bob, Donna and Sam’s perspective (for Robin did not participate in this very public activity), demonstrates what the *Benetton* image could/should have been.



Replicating the staging of the *Benetton* image in great detail - a father with a child (who they know to have an intellectual disability for this is a photograph of my husband and daughter) seated on a bench in a park setting on a sunny day – their staging of this image reveals both proximity and discontinuity from the original. Disrupting the violence inscribed in the original, this image diverges from the *Benetton* one in significant ways: there are no dark areas to hide or mask the father’s violence; the threat of the leg and boot has been removed; the intent of the father’s touch – the love - is plain to see. The group members, by this point in the project, have come to know my family well and to understand the relationship my husband and daughter share. Both were quite happy to pose for this photograph and the way they are seated is, for them, a very comfortable and natural way of being together. Pointing to the original, the transformed image represents for the group their hoped-for version, what the image could/should have been. Once completed, they had remarkably little to say about this photograph, other than it was “better”, “this is more like it”.

Throughout his participation in the project, Sam subtly speaks to his belief that people with disabilities not only want love, they are also capable of giving love, of being caring people. Typically, these discussions occurred outside of our meetings: sometimes while waiting in the lobby for all the group members to arrive, sometimes on the subway, sometimes while talking to other people about the work. In one meeting, Bob shared an anecdote about his pet birds and

how he had to give them up because his social worker felt that he couldn't take care of them. This recalls numerous conversations Bob has had with me on our subway rides home from the meetings. Many times Bob has told me about how much he likes having pets and his concern over their vulnerability and whether he can properly care for them. He has been told by his social worker that he cannot and his relinquishing of his birds suggests that he goes along with this (although I wonder if he has any choice?).

Donna expresses this sentiment in what is, perhaps, an even more painful example. She talks often with me, outside of meetings, about her sadness over never having been able to be a parent. I do not know if she was physically (un)able to have children – she has never mentioned this. But she has told me, several times, that her family and others actively discouraged her to the extent that she felt having a child was prohibited. She was further told she was not able to adopt a child – that because of her disability adoption agencies would assume she would not be able to adequately care for a child and would thus refuse her application. The second image the group created in the park speaks to this idea – that people with intellectual disabilities can and do care and love – and speaks against the opinions of those who think that their intellectual disabilities preclude this possibility. As a condition of possibility, this imagining, for Donna, allows for a different story; it will tell people that she can love a child and that a child could love her. Suggesting a mother-child relationship, in the same way that the *Benetton* image of the woman and child and the group's second re-imagining of the *Tracy* image do, the group's staging of this photograph of Donna and Frances further (unintentionally) makes use of a religious framing – a Madonna and child imagery. (It was, in fact, Ted who framed the image this way. In trying to ensure he captured the group members' intentions, he would typically take a number of photographs, frame them based upon what the group members were articulating and asking him

to do, and then present these to the group members either for selection of the image they felt represented what they wanted to say or for further revision. This image of Donna and my daughter was Donna's selection.) While, like *David*, the image is bordered in black, the darkness in this image works differently than it does in the *David* image: surrounding Donna and Frances, it is as if the viewer is permitted a look inside, a glimpse of an intimate, loving moment.



The notion that people with intellectual disabilities can and do care and love is a sentiment that is similarly present in Bob's transformation of the *David* image. In a meeting devoted to discussing how to change this and other images, I asked Bob what he would like to do, how he would like to change the image to let people know how he felt about it. Bob wanted to alter the image in such a way as to demonstrate his care and concern for *David*, his efforts to protect and keep *David* warm, to afford him dignity and save him from embarrassment. For Bob, this could be readily accomplished by covering the man in the photograph with a blanket. With little fanfare or discussion, and absolutely no dissent from Sam, Donna or Robin, here is Bob's re-imagining of this image.



Ann: Do we want the words? Do we want to put the same words, "*David means beloved*" with the blanket picture?

Sam: Sure.

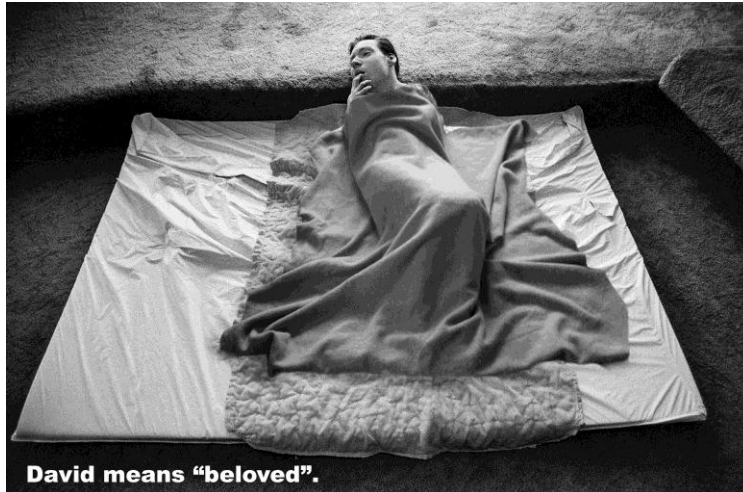
Bob: That is okay.

Donna: Yeah, that is okay.

Sam: That is a good word.

Bob: You got to tell about his name.

Robin: You have to tell his name and what it means.



Chapter 9 – Weightless

Introduction



Sam: It looks to me like he can't move properly because he doesn't have the strength and he also can't have the energy either, he doesn't have the energy and, uh, he's also, like, very bony and, uh, also because it's very tough for, for people, for, um, thin people to move when they don't have enough muscles and he, he doesn't, plus he can't have any strength in his, in his inner being as well, too, inner strength as well

Ann: Why can't he have inner strength?

Sam: The reason why he couldn't have any inside is because, um, it's just very hard for him because he doesn't, he's not really that strong, he's weak.

Ann: So, if he's physically weak, like he's weak on the outside, that's going to make it harder for him to be stronger on the inside?

Sam: Well, maybe if there had been something, if there had been a way to take care of him [e.g., oxygen, therapy, food]...he's weightless, 'cause he doesn't have a weight, that's the problem, that he can't move cause no weight...He can't move as much, he is institutionalized and can't function as much as us. He has no strength or energy, he is too bony, no muscles. No inner strength either because it is too hard for him because he is physically weak, is weightless, has no weight.

Sam is held captive by the staging of *David's* physical body in this image; a body he regards with great consternation and alarm. Holding the image in his own large hands, he is unable to contain his concern and worry – it is arrestingly etched on his face. *David* is terribly thin: as he works with the image, Sam is transfixed by *David's* emaciated limbs, his bony knees – legs tightly held together as if fearing he may break, his slender frame and visible ribcage. Being this thin, without any muscle, *David* has no energy, no strength. He can neither move nor function. For Sam, *David's* body is barely tolerable. As the centerpiece of this image, this body is achingly present, yet it is a presence firmly rooted in absence – the absence of body mass, strength, and energy; the absence of “weight”. It is the absence, too, of any signs of life around him, of a life lived or lived with others. The absence of these markers accentuate the constructed “weightlessness” of *David's* body in the image: without context, *David* is hard to grasp; his body barely touching the mattress and blanket under him, he appears so light as to be at risk of floating away; un-rooted, he cannot be held, cannot be known. Like Sam, Bob, Donna and Robin are similarly alert to *David's* physical presence, similarly labouring to make sense of this seemingly weightless being.

In the fragment above, Sam regards *David* as having no “inner strength as well”. At first it is not readily apparent what he means by this (does he mean *David's* internal physiology – his heart,

lungs, or other organs - is similarly weak? Or does he define “inner strength” along more conventional lines, thus understanding *David* as lacking, perhaps, moral fortitude or strength of character?). Uncertain, I initially let it go. Sam blames a lack of care and institutionalization for *David’s* lack of movement, function, and strength. Yet, as Sam, Bob, Robin and Donna work with the image, and return to it again and again over the course of the project, coming at it from all sides, their conversations move me beyond their surface interpretation of *David* as being literally (physically) weightless. I come to understand they also mean ‘weightless’ as metaphor. *David*, and other people with intellectual disabilities, “have no weight”, no influence or clout – over their own lives, over others, over how they are represented – nor much ability to effect change. Rendered physically weightless, both by a lack of proper care and through incarceration in an institution (with obvious implications for further physical degeneration), *David* can no longer do for himself, and (equally, if not even more disturbingly) he is further incapacitated through a consequent denial of opportunities to ‘function’ in a different sense – as a valued presence, a person of substance. Un-rooted, with only the most precarious (if any) connections to others, *David* lacks gravitas; he is denied a meaningful presence, influence, agency, and power over his own life.

It is this duality of meaning of “weightless” that informs this chapter. Braiding their own experiences into their thoughts about *David* and the persons with intellectual disabilities in the other images they select, they reveal their own intimate feelings of powerlessness. For some, these interwoven conversations expose their doubts about their own physical (and other) abilities. At times, their self-perceived failure to exert control over their own actions diminishes their sense of self. More often, they are contending with others’ dismissive and discounting responses to them. Confronted by these interior and exterior enemies, by their impoverished

sense of self and the maleficent power of non-disabled others (and visual representations of people with intellectual disabilities produced by non-disabled others) over their lives, they tell me they often back-down. Yet, later in the conversations, their words reveal not only the impossibility, but also the possibility of power, the ways in which this ‘weakness’ could, quite easily, be re-framed as subversion, as strength. This re-conceptualization of people with intellectual disabilities as power-‘ful’ is most striking in their reworking of three public photographic images – *David*, the *United Way* image, and the *Burton Blatt* image – and it is through their work with these images in particular that the multiplicity and instability of their meanings of “weightless” are unearthed.

Weight-less (Power-less)



Donna: I wish I could do something for him but I can't, but, um, God's probably gonna be with him and, and he'll be, he'll be looked after.

And later,

I feel sorry for people like that, you know... I wish I was experienced in that field to work with people and help people, you know - I love to help people you know.

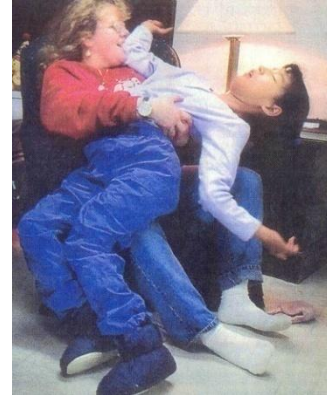
Donna's placement as viewer, spectator, to this image produced by (non-disabled) others, places her in a reactive position. What Donna quietly admits into the conversation is her own sense of powerlessness. She would really like to help the man in the *David* image; she would, but she

can't – she doesn't know how. But this takes on a much greater urgency in her work with the *Tracy* image, work which unleashes a rush of emotion directly linked to her own experience. It reveals an engagement with the image that moves the act of viewing far beyond the conventions of detached spectator. With arms crossed on the table, Donna thoughtfully gazes at the image in front of her for a minute or two. Closing her eyes in concentration, she then begins to speak to Sam and to me:



At this meeting, only Sam, Donna and I are present. The room is small. The walls are white and unadorned. The three of us are sitting at a table: I sit across from Sam and Donna, facing them, they are facing the video camera. We have paper copies of the images in front of each of us. It has the feel of viewing a taped confession.

Donna: To me, I would find it very difficult, I don't think that I could do it, I could lift somebody like that, I don't think. I mean, like, uh, I just seem, like uh, I don't know, it just seems very difficult to, to uh, to um (pause), it just seems to me like it looks difficult, getting her out of the wheelchair and sitting her on her lap. I'm wondering how, how can somebody look after somebody that's in a wheelchair, that puts her in the bed, takes her out, wash her and dress her, feed her – see, I couldn't, I can't, I can't, I couldn't handle somebody that was in a wheelchair like this or somebody was blind. I *could not* look after them, for, number one is, I'm not taking full responsibility for something. If something ever happened to that person I don't want to be responsible 'cause I don't want to, uh, like, I would feel like *I'd* be responsible if something ever happened, the person fell or had an accident or stuff like that. You know what I mean?



Sam: Or if it gets hurt or something. This is very hard to listen to!

Ann: What's hard to listen to?

Sam: To hearing about, uh, if the person got hurt, if the person fell or like break bones, er, even uh, had bruises or stitches because if the person was just, um, from the wheelchair or something, if the person, like, had to like have a lot of responsibility to take care of the wheelchair person, the person in a wheelchair I mean, um, and it depends because, um, some people who have a physical or intellectual disability or, um, have a supplement inside, they basically like, maybe like, wiggle and shake to death and if they're carrying, it's very hard for the person to handle or anything, and then I know the person who's carrying it might, like, feel very sensitive about that, er, they would have to, kind of like, keep the person conscious or in line to make sure that the person is, like, wealthy [healthy].

Like Donna, Sam appears more attuned to the situation of the person giving care than of the young girl receiving it. Listening to Sam speak, I wonder to what extent, if any, his responsibilities for assisting his mother in caring for his ill and aging father directs his response. Sam tells me often that he is actively involved in his father's daily care, yet this has always been a mechanical recounting, one that has not invited an inquiry or revealed very much about how he feels about it.

Donna: Well, that's what I mean, too! That's what I mean! I don't want to be, like I don't want to be responsible if something ever happened to somebody that, uh, I just can't deal with it, I mean, I got enough problems! I gotta live my life, I gotta look after myself, I can't worry about somebody that's in the wheelchair, that, that's blind and it has seizures and this and that, it has Down syndrome. I can't worry about all that. I have enough problems that I've been dealing with over the years and I'm, I'm so sick, so *sick* of it all, and, uh, I'm tired of people, I'm tired of people, of being pushed around and I just, I just don't like it anymore! I'm sorry, but I mean that's the way I'm feeling. I just, I'm not gonna be responsible. If someone fell, if someone fell on the sidewalk I, I'm definitely not gonna stand there and say "are you OK?", I'm gonna walk away because I don't, not want to get involved with it and I don't want to be, because, I don't want to be, I don't want to be *responsible* for anybody's wrong doing...

I feel dismayed whenever I hear Donna or the others apologize for their opinions, their feelings, and their decisions (in this case, to not offer care to others) despite my understanding of the likely origins for this self-devaluation of their thoughts and perceptions. The degree to which it is embedded in their conversations is troubling.

Sam: Right...or, like, get in trouble or be accused of doing something, but that's not true [be accused of something that you did not do].

Donna: Yeah, you could be accused of something, if, if, they, they could, could accuse you for something, you know!

Sam: Yeah.

Donna: They're gonna ask you questions: "Did you hit this person?" "Did you?"

Sam: Or, "Why did you do this?", this and that and they might...

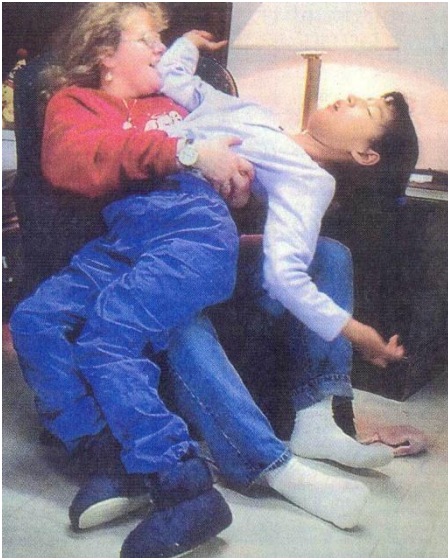
Donna: Yeah.

Sam: ...probably, like, *arrest* you for something you didn't do in the first place!

Donna: Yeah, yeah, like, that's what I mean!

Ann: Did that ever happen?

Sam: Um, well, as a matter of fact, no, that never happened [he was never arrested], but I know how does it feel, like maybe just in school I been accused, um, a lot of times, maybe for, uh, what's it called, just for other personal issues but I didn't want to get involved in it or something, but all of a sudden...I'm glad that, um, I'm glad that I just got over it, just didn't let it bother me or anything but if, uh, what's it called, if it does ever happen or something then I just have to make a good way how to make sure that it gets, um, settled, and then just resolved, um, this conflict issue and then just, uh, and then make, and try to get to, get to the point of what the plan is so people would get it and or so, but people just have difficulty understanding it then, obviously, or so, then I would just have to be strong about it to know exactly what's going on and what makes sense!



Divulged by this exchange are Sam's and Donna's own feelings of vulnerability and

powerlessness and the intertwining of care and power. Beginning the conversation calmly, Donna admits to believing herself physically unable to lift the girl out of the wheelchair and her sense that such a task requires far more strength than she possesses. Whereas in the *David* image the absence of responsible others is a significant presence, in this image the carer is central, very much physically present in the image and, by implication, in the girl's life. Having positioned herself in the place of this woman Donna reveals her wish, her will, to care for the girl (for others) but, with voice rising, she recoils from the long list of the girl's overwhelming care needs: lifting, holding, bathing, dressing, feeding – "I can't do it!" Her tone expressing disbelief (and sometimes awe), Donna struggles to understand how someone could, physically, manage (what she perceives to be) the back-breaking task of caring for a person with an impairment such as this young girl has (or, for that matter, caring for someone who is blind, has seizures, or has Down syndrome). She is adamant: "I *could not* look after them!" With this image she has moved from concern over her inability to care for the weightless body of *David* to an equally distressing realization that she cannot care for *Tracy's* body either, a body that (in contrast to that of *David*) is too heavy, too difficult to care for; a body that in contrast to the diminutive frame of the carer holding this girl, has been staged to seemingly bury the carer under a weighty, flailing body she struggles to hang on to, thus exaggerating the burden, the impossibility of the task. Donna reacts to this staging but, consequent to her own experience, the trace of others she has known in the image, she also grasps the reality of the amount of care that some persons with intellectual disabilities would need. Like *David*, this young girl requires more than Donna can provide; both are more than she can bear. This is a responsibility/response-ability that is too much for her, too weight-ful to be managed. But she then broaches a notion that is quite quickly rendered more grievous, more pressing to both Donna and Sam – the notion that with responsibility (for another), comes risk. At first, Donna's reluctance to assume responsibility for

caring for the girl reveals her anxiety over holding herself responsible, her worry that the person might be hurt in her care. Gesticulating with her hands, she says, “*I’d* be responsible if something ever happened.”

While Donna speaks, Sam listens respectfully, his eyes upon her. Here, however, he tentatively steps into the conversation. As he did with the *David* image, Sam appears to anticipate or assume that the girl *will* be hurt, that she (like *David*, and people with similar impairments), is at a constant risk of injury or being harmed: “falling”, “broken bones”, “bruises”, and “stitches” all await her. Speaking directly to me, he remarks that caring for someone with these types of impairment demands “a lot of responsibility”; a responsibility that, he assumes, caregivers take very seriously. His hands patting downwards, as if signifying a subduing or controlling gesture, Sam tells me what is required to keep someone with a disability “conscious”, “in line”, to keep them well. But, at this stage of his engagement with the conversation, Sam concedes only that he would find it very hard to *hear* about someone being so hurt. Guarding himself, his involvement is such that *he* would not be the one responsible for the girl’s care and, by extension, for any harm that might befall her.



Donna explains her reluctance, her refusal, to get involved within the context of her struggle merely to manage her own needs – “I got enough problems! I gotta live my life. I gotta look after myself!” Shaking her head, she speaks and looks squarely at me until I acknowledge that I understand: “I’m so sick, so sick of it all, and, uh, I’m tired of people, I’m tired of people, of being pushed around and I just, I just don’t like it anymore.” As she sits back in her chair, I hear her fatigue, her weariness over the stresses faced daily in her own life, the toll these battles take, and the alarm she experiences when asked to consider caring for another. From her position, this would be far too much and she would have little choice but to “walk away”: faced with someone like *David* or this young girl, Donna would, in fact, refuse this responsibility. Considered within the context of Donna’s earlier comments that unveil the importance of caring, the value of caring for another that is central to her sense of self, this is a painful decision that creates conflict for her, a decision she feels she must apologize for. But, within this fragment, Donna twists the notion of holding herself responsible to being held responsible by others *and* to being unjustly held so. Jumping in, Sam makes this even more explicit, introducing the language of accusation and blame – he does not want “to be accused of doing something, but that’s not true.” As the discussion ping-pongs back and forth between them, Sam’s and Donna’s individual comments triggering a response from the other, the tension intensifies. The accusation becomes more and more authoritarian, more and more violent: interrogation (“Did you hit this person?” “*Did you?*”), evolves into blame, an assumption of guilt (“Why did you do this?”), and then scapegoating. While he is insistent he did not do those things he was accused of doing, neither can he undo the blame and damning condemnation. Using his index finger to forcefully punctuate the air, Sam names the most likely outcome – arrest, for “something you didn’t do in the first place.”

With some alarm, I ask Sam if he had, indeed, ever been arrested. While he has not, he reveals a long history of false accusations and his attempts to manage these, to just get over it and not let it bother him. But he also makes plain his (to my mind, troublesome) surety that he is continually being watched and his certitude that this unjust blaming will happen again – that he is impotent to prevent such accusations but must try to protect himself. Throwing back his shoulders as if bracing for what might yet come, he calmly says that he must focus on staying “strong”, on (resignedly?) taking up responsibility for the resolution of this conflict – from where he stands, the onus is on him to defend himself against his (more powerful?) accusers. Then, shaking his head, his body slumping, Sam feigns a nonchalance that fails to mask the precariousness of his position, and how troubled he is by the apparent truculence of others and their unwillingness to acknowledge his side in these situations. As the project proceeds, Sam recounts numerous incidents of being unfairly blamed for things, being wrongly accused, and of people attempting to implicate him in situations he did not want to be involved with. Sam, as noted, is a big man – tall and strong – quite unlike the man and young girl in the *David* and *Tracy* images, respectively. Unlike them, Sam appears, at least physically, able to protect himself but, as the layers of his experience are revealed, the pervasiveness of his lack of power is made plain. He tells me how, in the past, he often reacted aggressively and this, he feels, may have predicated his placement in a ‘special’ program at a psychiatric institution.

I wonder, often, what he has experienced; most painfully, when I watch him around my daughter. Frances is a very affectionate child who very much likes Sam (and the other group members). She quickly runs to hug him in greeting but Sam will not reciprocate – instead, he immediately (and consistently) raises his hands high above his head and waits for me to intervene.

Donna returns us to her concerns a little later in the conversation. Asked how this image makes

her feel, she pauses, then yokes the image once again to her own feelings of helplessness in a life she finds overwhelming, and over her own emotional and behavioural responses to it. This image is too much to bear.

Donna: Well it makes me feel, like, upset. I feel sorry for this person, you know. I do feel sorry for people. I don't make fun of people because of the way they were born. I accept people for what they are. Just 'cause sometimes I get upset and get angry doesn't mean to say that I'm, I'm, I, sometimes I say things and I really, *really* get really upset and um, I just find it very depressing um, 'cause I see enough of it on the street, I see enough of it on the subway.

Ann: Do you find this picture depressing did you say?

Donna: Yeah, a little bit, I just find it, to me, I find it, uh, well, it just kind'a bothers me 'cause I feel sorry for her, you know, for this, this woman. I feel sorry – if there's anything I can do to help, you know, but I feel really sad, you know... I got, I got nothing, I got nothing against anybody, I, I love everybody but, I mean, I just can't, I don't know, sometimes, you know, I don't know, I just find it very difficult to deal with. I have, you know, I just find it, uh, um, very upsetting, you know.

Ann: The picture? Or life in general? Are you talking about the picture now or are you talking about life being very difficult

Donna: Life; and I'm also talking about the picture, too.

Ann: The picture is difficult? What you see is difficult? I just want to make sure I understand is all.

Donna: I just find it very upsetting 'cause I really feel sorry for this person. I really feel sorry, I mean, if there's anything I could do I'd like to help but, unfortunately, I can't be the one to deal with it, like, I can't, I can't, I like to help, 'cause I am a kind-hearted person sometimes, sometimes I can be a little bit moody...



The girl in the image has been positioned in such a way as to emphasize, if not exaggerate, her vulnerability. Perilously sprawled across the woman's lap; limbs askew and dangling; head

hanging backwards as if barely tethered to her body, her inability, her helplessness, her dependence (and the woman's seemingly flimsy hold) grab the viewer's attention. Donna's concern for the girl in the image is palpable. So, too, is her distress over her inability to assist her. Donna pronounces that she doesn't make fun of the young girl for her disability, that she accepts "people for what they are". Quick on the heels of this claim, she begins to try to explain how she sometimes gets "upset". Stressing this ("I really, *really* get really upset"), it seems important to Donna that I understand. Her coupling of these two ideas here only lightly veils her confusion over why she, herself, is not similarly accepted by (non-disabled) others. At other times during the project (typically upon arrival, before the meetings' start), Donna's restraint is tossed aside and she speaks frankly and fiercely about her hurt and anger when others misuse their power over her to make her feel badly about herself and to provoke her. At these times, she makes explicit, the (to her) straightforward cause and effect relationship between this rejection and her powerful, and (by her own admission) fearsome and intimidating, expressions of sadness, pain and anger; behavioural outbursts she (unlike Sam) feels powerless to rein-in.

The *Tracy* image is upsetting, just another example (much like the *David* image and the many people Donna witnesses in their daily trials on the street and in the subway) of a depressing world that confirms for Donna her sense that people with disabilities are forced to suffer, a useless and unnecessary suffering, and that there is very little that she, herself, can do about it. As she says, "...I got nothing" and, while the rest of this sentence suggests she is speaking about a lack of prejudice ("...I got nothing, I got nothing against anybody, I, I love everybody"), her subsequent re-iteration that she can't help the girl, implies a second meaning – an expression of her feelings of helplessness when confronted with life's challenges. Weaving together, as she does, her thoughts about the image and about life, I am not certain I can disentangle the two and

I ask for clarification. She quickly turns to face me, glaring as if my words are thrown at her as opposition or provocation. This flash of anger quickly subsides as I hastily explain myself and she then, with head shaking, says again that she can't be the one to help, "can't be the one to deal with it".

Encapsulating Sam and Donna's concerns is disheartening, in particular the messages they have received about their own incompetence. Believing herself physically unable to care for others, Donna's first worry is that someone in her charge might be hurt. Donna and Sam both speak of themselves as being dangerous to the young girl in the image – and they recognize further that they are regarded by non-disabled others as dangerous to many. Both she *and* Sam are steadfast, firm – this type of responsibility (that of caring for another) is beyond that which they are prepared to take on: they have, already, far too much on their plates just dealing with the day-to-day and, besides, it is much too risky. Keenly aware of the threats that exist in the form of non-disabled others wielding power over them, they know, too, that escape from the inevitable repetition of blame is impossible but that retaliation is dangerous. Embedded in their accounts, however, is evidence of strength – precedence is given to protecting the self.

Power-ful

The narratives associated with the group's work on the *Burton Blatt*, *United Way*, and *David* images tell other tales that re-position Sam, Donna, Bob and Robin as 'power-ful'. In these narratives, their strength, their 'weight' is made visible and/or claimed.

Punishing the punishers.



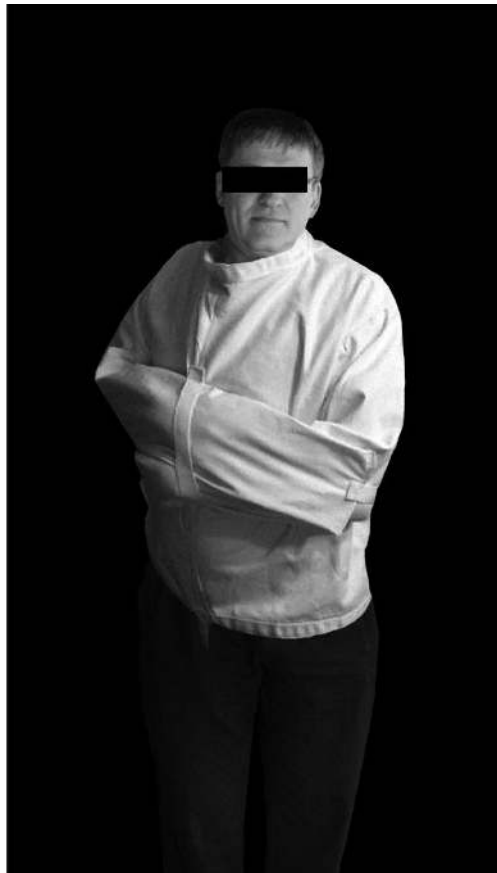
Sam: Um, it also really tells that, um, that people, um, doesn't want the, her, um, in the house because she has a disability and, uh, the problem is because, uh, they don't like, they don't honestly approve, and don't honestly, are ever having been keen on being honestly caring or supporting or think about people with disabilities about what their feelings and how, like, their averages are like or so. And all, all of a sudden or so, even if they send them to, um, to place where they're not supposed to be, that's wrong, you know, because that's all honestly a very bad attitude, a bad gesture, and even a bad opinion as well. And what these people do are like very, um, corrupt, and they're just low-life, and definitely they, they, they should be punished for how they would do that to, um, a child with disability, that's very, *very* wrong!

Given the intensity of his words, Sam's body language is remarkably subdued, yet this may be explained by fatigue (physical? or an emotional fatigue stemming from the work?). Typically exuberant, today Sam looks tired. He sits, slumped in his chair, resting his head alternately in his hands or on his shoulder. He echoes Robin's assertion (regarding *David*), that the little girl, like all people with intellectual disabilities, is not wanted – she is cast out of “the house” (in the literal sense, cast out of her family home and out of the mainstream, but also out of a more general sense of belonging – to a family, a community, to the world) and incarcerated – (like *David*) locked away in the dark and punished because of her disability. For Sam, this is what the image “really tells” the viewer; this is an honest telling of what has been inscribed within. In this case, what he reads as the ‘truth’ in the image is, indeed, the truth. While horrible enough in and of itself, it is not quite so simple for Sam: not only is she not wanted, non-disabled others

actively disapprove of her and have scant interest in caring for or about her, or in supporting her. As Sam carries this train of thought through, he determines that, for non-disabled others, how people with intellectual disabilities feel never enters their consciousness, never impacts their thinking. The little girl in the image (like *all* people with intellectual disabilities?) has been judged to be lesser; unworthy of the attention, interest, or effort of non-disabled others. She is weightless. He introduces a new meaning of ‘weightlessness’ – of little (no) import, the child’s thoughts, wishes, opinions do not count: beyond being heard and discounted, they have not even been sought – the child is weightless in the eyes, ears, minds of non-disabled others. Responding to her (otherwise) unheard call, speaking up for (as) her and, thus, bringing her out of the dark (Derrida, 2001a), Sam admonishes that this is all “wrong” – both non-disabled thinking about disability (“a very bad attitude”, “a very bad opinion as well”) and behaviour (“a bad gesture”) towards people with disabilities are faulty. Recasting himself as judge, not judged, demanding retribution, Sam angrily delivers his verdict – that the “corrupt” “low-life” who would do this to a little girl deserve to be punished.

As Sam speaks, the others listen, nodding in agreement. I ask them how they might change the image to let non-disabled people know how they felt about it. Pausing to consider their answers, they circle back to Sam’s feelings about the image, lighting upon his exhortation that the people responsible for the girl’s treatment be punished for what they had done. Reminding them that, in this instance, they are in charge, I press them to consider how, “How can you punish them?” Becoming more and more angry, they reply that those who are “guilty of doing this”, the “evil men” who “cause the trouble, who do this to make people feel uncomfortable”, should, themselves, be put in straight-jackets so that, as Donna forcefully yells, “they feel what it is like!” Turning the tables on those in positions of power, the group instructs Ted and I to find a

man, a white able-bodied man, a bureaucrat who was responsible for such treatment of people with intellectual disabilities, and put him in a straightjacket^{xviii}. Their transformation re-paints the man as being as powerless as the child in the *Blatt* image. Its staging - the straightjacket and the black band across his eyes (which directly mirror the image of the child), the black background and resultant absence of any other information or markers of time or place in the image – works to decontextualize the man: his (now erased) master status (white, able-bodied, bureaucrat, powerful) no longer exerts any hold over his situation (or the viewer's reading of it) and, like the little girl, he is rendered without a history, without a (livable or lived) life. Bearing as it does the trace of the original image, this re-imagining works to de-stabilize that which is inscribed in the original.



Controlling the name/game.



At the start of the first meeting to discuss this image, everyone was excited, upbeat, interested.

As with all of the images, they knew little about the image. Stripped of its caption and text, they did not initially know it accompanied a charity advertisement, only that it was in the newspaper.

Donna put her glasses on before contemplating this photograph of a group of people with intellectual disabilities. Absorbed in the image, they were quiet for the first several minutes.

Bob was the first to offer his interpretation:

This really surprises me. Bob most often sits in the middle of the group, quietly listening and watching the others. He, typically, defers to others; waits for them to speak; stops talking when others interrupt him. Sometimes he even directs the others to offer their opinions first, citing the “good ideas” they have. But he is clearly interested in this picture and firm in his interpretation of it.

Ann: First, off, I want to know, when you look at this picture, what do you see?

Bob: Well. I see them smiling.

Ann: You see people smiling?

Bob: Oh yeah. They’re all smiling. I guess they’re happy.

Ann: Yeah? That’s what you see? You see people smiling so they’re happy?

Bob: But I’m not sure what they’re thinking about.

Ann: Do you have any idea...like, what you think they might be thinking?

Bob: I like to think they might all have jobs.

With naught but the six neatly dressed people grouped together, comfortably pressing against

each other and the image's edges, bodies (if not always eyes) directed towards the camera, Bob immediately responds to the mood and relational atmosphere of this black and white image – a grouping of people whom he understands to be happy, to belong to the (un-disabled) world (of work). (Although photographed in black and white, the image is generally bright – only the fading due to age, a fading immediately recognized by the group members, works to darken it to any degree.) Donna concurs with Bob: in this image (dramatically different from the *David*, *Tracy*, and *Blatt* images) she, too, sees a gathering of happy people when she looks at the photograph – they look like friends or, perhaps, a family. Concentrating her attention on the man in the image with Down syndrome, Donna provides a possible explanation for their happiness, declaring, “It looks like he’s happy to be with every, everybody in the picture.” She goes on to offer her reasoning for this assumption: *I’m* always happy when I’m around people, it always makes *me* happy.



With a broad smile, Bob is pleased by Donna’s answer. He, too, is happy when with others and his own, and others’, happiness is very, very important to Bob. Desiring, again, a story, amongst themselves the group members arrive at one that diverges greatly from the stories they have told about *David*, *Tracy*, and the young girl in the *Blatt* image. They surmise this particular image is about a group of friends, friends who all have intellectual disabilities, but who enjoy each other’s company and who are not ashamed of their disability or of themselves. On the contrary, wanting to be recognized, they are “honest” about having an intellectual disability. Robin extends this further, believing that the people in the photograph had instructed someone to take this

photograph, the photograph that *they* wanted - a picture of them together as a group, as friends. They are thus both *in* the image and the *producers* of it.

I wonder how non-disabled viewers would interpret the image, what stories they would read in it about people with intellectual disabilities.

Ann: What do you think the picture says to non-disabled people about people with disabilities? Something good? Or not so good?

Donna: I think it would tell them something good about them.

Ann: OK, what would it tell them? That they're happy?

Donna: Yeah, that they're happy, and that people that don't have a disability, and then if the people that have a disability explain to people that don't have a disability, and then they would, they would understand where we're coming from, and then they would think and they would realize, and then when they look at these pictures they'd realize that they said something wrong and it's very hurtful and they shouldn't do that. That's my way of thinking; I don't know how to put it any other way.

Thus, viewing this (de-captioned) image, offers a possibly disruptive understanding of people with intellectual disabilities – a re-conceptualization of them as happy, content, unashamed and (at least partially) comfortable with who they are. But Donna seems also to indicate that, alone, the image may not be sufficient. People with disabilities, if given the opportunity to address people without disabilities (visually and/or in dialogue), can be effective agents of change. If regarded as experts and given the authority to define and articulate the experience of disability – to “explain” - *and* if listened to, they can enlighten and trouble non-disabled meanings of disability.

In another meeting, Robin and Bob assign the image a different function and assert the image should only be shown on its own – it would be best used as a personal photo, “for memories”, “like a family snapshot” that you would keep in your “photo album”, “journal”, or “life book”.

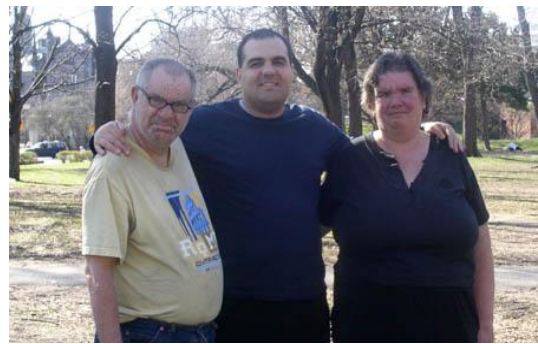
This idea resurfaces in one of the last meetings we have and leads to their first visual response to

the image. Wanting to focus on the image as representative of a group of friends, Sam and Donna offer for consideration the idea of pairing this image (without caption or text) with some of their personal photographs. Robin assertively declines – he is adamant in his refusal to be publicly represented visually. Bob, also, quietly demurs and then explains that he does not have photographs to contribute. The group’s solution is to have Ted take photographs of Sam, Bob and Donna (photographs that they direct) and present these alongside the *United Way* image, a pairing that extends their photo album. Preferring colour to black and white, Bob, Sam and Donna nonetheless pose themselves in a manner replicating that of the people in the *United Way* image – smiling, close together, squarely facing the camera.

Donna: I want to use my pictures!

Sam: Me, too!

Donna: I think it would make it look nice, you know? Two pictures [the *United Way* image, and their personal photos] - it would make it look nice.



This hopeful reading is soon tempered. Over the course of their work with the *United Way* image, Bob, Sam, Donna and Robin stress that the problem lies, not so much in having an intellectual disability, as in how non-disabled others respond to such. The people in this image would not be ashamed of themselves. If kept private, the images are pleasing, affirming, something to be treasured and held (and something that other persons with intellectual disabilities – such as Donna, Sam and Bob – would be comfortable identifying with and

admitting to: the image welcomes and invites this identification). Undoubtedly, they would, however, be “nervous” or “worried” over non-disabled reactions to public displays of their image. If used outside their personal and private worlds, taken and used publicly for any reasons (e.g., advocacy) that entail communicating with the un-impaired, the image becomes dangerous. The *United Way* image, itself, exerts a kind of control over their lives and in its own way is understood to be as dangerous as the *David, Tracy, and Blatt* images. As Donna tells me, non-disabled people instantaneously “pick up” on visible disabilities in public images. Speaking to the tyranny of the visual regime in disability, to its (mis)use as surveillance, as a mechanism of discrimination that has proven difficult to overturn, she makes plain her unease, her apprehension. Using visual imagery against all people with intellectual disabilities, not only against the subjects/objects of the image, many non-disabled people, when presented with an image such as this, are “gonna make fun of people”.

Donna: I don't think I would, uh, um, I don't think I want them to see my picture, if they're gonna, if that's the way things are gonna be, if they're going to go around and do that kind of stuff, then I don't think, I don't see any point, you know, in showing the picture. What happens if they laugh, or say 'oh, lookit, she's got a disability', 'she's this, she's that', you know? You know, how would I feel?...I've had people make fun of me and it's not very nice, it's hurtful. And it's *not* very nice... Sometimes I feel like, just, oh, I really get angry, boy, oh my god, I feel like, um, you know you feel like you wanna, you wanna, uh, I don't know...

Ann: Just throttle somebody, right?

Donna: Yeah, and I, I, I, uh, I try to hold that back 'cause I, I know what's gonna happen to me...

Bob: Right.

Donna: ...but I try, what I'm basically saying is that if they make, they make, um, people that don't have disabilities, they don't even know what it's like until they're in my shoes and know what it's like... I don't make fun of anybody.

Speaking with a mix of anger, sadness and derision, Donna articulates how not merely the subjects/objects of the public images, but *all* persons with intellectual disabilities, are at risk for each image is believed to subsume, to represent, to mark all persons with intellectual disabilities

as the same – “oh, lookit, she’s got a disability’, ‘she’s this, she’s that’.” The images are dangerous. The repercussions are painful. Yet, as Donna again makes clear, the threat to people with intellectual disabilities is two-fold, for to react against the images and to non-disabled viewers’ responses to them, especially with anger, is to court punishment. Sitting bolt upright, while slapping her copy of the image against the table repeatedly, she lets us know that, for her, such punishment is all too familiar: “I know what’s gonna happen to me.”

Later in this conversation:

Donna: I’m just letting you know that, that, you’re asking me that people that don’t have disabilities, I’m telling you that if, you know because I’ve had people laugh at me, I’ve had people back-stab me, talk about me behind my back and call me all kinds of names and make all kinds of trouble for me and, and I really don’t need that in my life. I’m trying to get ahead in life, and if people are gonna go around back-stabbing me, talk about me behind my back and don’t say anything to my face, and I then hear about it – oh God help them! You know, I mean, like, I’m under enough stress as it is and I gotta be careful what I’m doing here, I got health problems and I can’t be dealing with, you know, uh, things upset me, you know, things really bother me, I get to the point where I just wanna, really ohhh, you know, sorry, sometimes things really just bother me.

Bob: Sometimes we all feel like that, Donna.

Escalating quickly, Donna yanks the conversations back to the topics of risk and danger – that faced by others who upset her in these ways (“oh God help them!”), and that which she faces and from which she must protect herself (“I gotta be careful what I’m doing here”). As she speaks, she clenches her fists, bangs them on the table and then, when telling Bob and I she needs to be careful, holds her hands open wide as if to push back against something coming at her. Listening attentively to Donna, when she finishes speaking Bob, very quietly (albeit assertively), claims this anger for all people with intellectual disabilities.

Let me, here, remind the reader of something Donna said during this discussion:

Donna: I don't think I would, uh, um, I don't think I want them to see my picture, if they're gonna, if that's the way things are gonna be, if they're going to go around and do that kind of stuff, then I don't think, I don't see any point, you know, in showing the picture.

Outside of meetings, they each recount tales of being teased, mercilessly, as a result of having an intellectual disability. Within the confines of this meeting, teasing is directly linked to visual media representations, making them distrustful of public images. This conclusion leads them to proffer that what might be best is to not have *any* public photographic representations of people with intellectual disabilities – to control the impact of public imagery by suppression. For the first time expressing some doubt as to potential of visual redress, they go on to say that if you *must* have public photographic images, then these images should “not specify it [intellectual disability] so much.” The marks of ‘intellectual disability’ must be hidden.

At this point, I furnish them with the image's caption, “*What's Wrong with This Picture?*”, and offer contextual information, advising the group that this was a charity advertisement, featured in local newspapers, with the express intent of raising money. Withholding their reaction, Donna asks if I can read them the entire text.

What's wrong with this picture?

You'll find the clue in those innocent faces. They tell you that these people can't possibly understand their most important challenge — living with dignity in our community.

The York Central Association For The Mentally Retarded helps developmentally handicapped people meet the challenge everyday. Through residential programs, parent relief, recreational activities, and foster care programs.

Our challenge is to help the Association keep it's services going. Money is at that scary balance between giving mentally handicapped people a healthy mix of life experiences and the reputation that will come with a lack of funding.

Let's keep the picture bright. Give them the support they need to help themselves. The United Way's 1985 drive for funds is now underway. The York Central Association For The Mentally Retarded, along with 26 other member agencies, is depending on you.

It's your United Way. Let's keep it working.

For more information on the programs offered by the York Central Association For The Mentally Handicapped call, (416) 864-9110 or (416) 699-0209

C'mon, cut it out... Now

Send today, support the drive tomorrow. Your helping hand makes a big difference.

Amount: \$10.00 \$25.00 \$50.00 \$100.00

Name: _____

Address: _____

City: _____

Province: _____

Enclosed is my cheque/money order for: \$10.00 \$25.00 \$50.00 \$100.00

Mail to: United Way, 220 Prince Street, Box 2, Mississauga, Ontario L4R 0A4

For more information call: (416) 699-0209

GIVE!

United Way of York Region

Donna and Bob unequivocally insist that the text alters their understanding of the image and, more importantly to them, would radically impact how non-disabled viewers would interpret the image. The text would not change how non-disabled others regard people with intellectual disabilities – it would serve only to make the image even more dangerous. With sad expressions, Donna and Bob both insist that the (bold-faced, black) caption – which spans the entire width of the image – and the text draw the viewers attention to the two people in the image with visible disabilities (Down syndrome) and, consequently, both announce and confirm for non-disabled audiences that “having Down syndrome or a disability is wrong”; the text determines and reinforces the prejudicial attitudes (and concomitant discriminatory behaviour) that already abound.

In work with the text of the image, the group reacts very strongly to the use of the label,

“mentally retarded” throughout the text. As Bob notes, the use of this term labels all the people in the image as “retarded”, whereas, without the caption, the disability was not always immediately visible. Donna “find(s) the word “retarded” offensive.” Picking up on this, Sam, in an anguished voice, says this:

We don't like the word “retarded” – it is offensive to us! It bothers us. It is not a nice word and people shouldn't use it. *Take it out!* People who don't have disabilities use this word to make fun of us, to put us down. No-one should ever use this word! It is very, very hurtful! We are all supported by an agency that used to use this word. But they don't use it anymore because people with disabilities didn't like it.

(Sam's command to, “Take it out!” interestingly corresponds to the text's own instruction to viewers/readers to “Cut it out...Now”, and shares its intensity. While Sam wants the word, “retarded”, removed from popular lexicon, the charitable organization is asking viewers to cut out the ad, donate money and thus (inadvertently?) subscribe to the word's continued usage and influence. None of the group members make this connection – in hindsight I wish I had pointed it out.) Speaking passionately, Sam links the prejudice inherent in popular usage of the now pejorative term to its use as a mechanism of power over people so labelled. Once more, the hurt that ensues from this prejudice is articulated. Yet, he simultaneously proffers a picture of people with intellectual disabilities as power-ful combatants, as people with influence (with “weight”), as he cites the successful efforts of self-advocates with intellectual disabilities to dictate the language that can, *and can no longer be*, used to refer to people with intellectual disabilities by a service provider. Their second transformation of this image reflects this usurping of power and taking control over how, as a group, people with intellectual disabilities are named/labelled. Removing the text and altering the caption, the image itself is untouched but the message, the ‘truth’ of the original image, has been disrupted enabling viewers to see otherwise.



As if to remind me of the tenuousness or fragility of this power, public use of the term “retarded” surfaces again, at the start of another meeting as they select which image to work on that day.

One of the images under consideration (but eventually rejected) dated back to the social hygiene movement in Canada, in the 1920’s and, in a four square grid pattern, presented four photographic images deemed representative of the four different categories of what is now termed, intellectual disability. The categorizations were: moron, imbecile, idiot, feeble-minded.

Sam reacts first, with a mixture of shock and dismissal. Gesturing with his hands as if to brush aside the words he says:

Sam: Why, why would they say ‘mongolian’? Like mongolian restaurant or something. That’s absurd, it’s ridiculous!

Ann: Yeah, but these are very, very old words, remember and so, like, back in the 1920’s and stuff they used these words but, you know, they didn’t think they were offensive before, but then we know they became offensive, right, and then they changed these words to things like mentally retarded, and instead of calling people an idiot, an imbecile and a moron, they called them mentally retarded, right, and now we know that they changed that, they don’t say that anymore, right?

Sam: Yeah.

But then, Robin speaks quietly, adding his concerns:

Robin: Sometimes people still do it...

Ann: Sometimes people still do it, yeah.

Robin: ...and still you can't do nothing, you try and try...

Ann: No?

Robin: ...it's hard.

Ann: It's hard when people do that.?

Robin: I don't like when they do that.

You need to ask permission!: Power through permission?

Robin, Bob, Donna and Sam, worry that the people in the *United Way* image would not have been informed of the text, the words that were to be appended to their image, nor would they have been told how the image would be used. In this way, they were “not being treated fairly, with dignity.” Once again feeling responsible to the persons in the image, Robin and Bob were concerned that they would be very embarrassed to learn what was being said about them and, again, how their images were being used, the purposes to which they were put. Robin, especially, was insistent that charities should never use pictures of people with disabilities for “it is too embarrassing and horrifying for people in the pictures.” Diverging from the others, Robin did not feel the caption was singularly an address *to* the non-disabled viewer made *by* the non-disabled producers of the image – an address instructing (reminding?) them that intellectual disability was “wrong”. Responding to Bob’s surmising that “the agency or someone else” must have initiated the production of the captioned version of this image (people with intellectual disabilities would *never* have done so), Robin complicates the group’s reading of the image and text (in a way that triggers their third transformation of it) by suggesting the address to the non-disabled viewer is being made by the intellectually disabled subjects within. They both ask, and answer, the question that is the caption: “*What’s wrong with this picture?*” For Robin, the answer the photograph’s subjects fire back at the viewer is this: “What’s wrong is that nobody asked their permission to take it!”



Don't use our picture without permission.

Here I wish to return to the group's work with *David* for this image provoked a most vehement admonition on the ethical necessity of consent.

Sam: I just don't know why that the picture would have to look like this, uh, why the person who's disabled would sit outside all day by himself in the middle of nowhere, and he doesn't have weight and he doesn't have strength and he's very thin and he's bony, yeah, and he's wearing a diaper as well, and he's not eating enough.

Having first introduced Sam's words in the chapter, "*Bob's Blanket*", I come back to them in this discussion. With his questioning, Sam accuses the producers of the image of using photography as another insidious means of rendering *David* (and, by extension, all people with intellectual disabilities) powerless, without (either literal or figurative) weight. He infers that it was not *David's* decision to be portrayed in this way, in this situation, causing the group to muse over who took the photograph? Why was it taken? Who made the decision to use it in the way it was used? Who was granted (and who was denied) the authority for this decision – and by whom? In another deconstructive turn, they move from questions of the inscribed 'truths' of the image to a questioning of the very production of the image. Their questions indicate their recognition that no images are neutral, that image-making is an act of power involving the subject/object, the

maker of the image, and the viewer: consent is relevant in each moment. They recognize, too, that all images have consequences (good or bad) for the subject/object of the image.

David, by virtue of the severity or all-encompassing nature of his impairment, does not possess the same degree of control over the use of his image as Donna perceives that she might have over images of herself. Speaking on *David's* behalf, with this image, Donna raises and tackles the question of 'consent':

Donna: Whose permission was it to take this picture? Who decided? Who gave permission to take this picture? Was it him or was it the family? That's my concern.

Ann: Why is this important?

Donna: Because you just don't take pictures without asking people permission first.

In this, as in all our meetings, Robin speaks from outside the video camera's frame. He refuses to be captured on camera, carefully checking with me each time that he is not within its range. On tape, his disembodied voice is only rarely augmented by glimpses of his hand gesticulating as he speaks.

Robin: They probably take it for reasons they don't care, they just take it, that's how they are.

But who, I wonder, is meant by "they"? The photographer? People without disabilities who solicited the image? *David's* family? Talking with Robin, I think he means to include them all – whoever it was who had a hand in the production and distribution of this image, in the silencing of *David* and his exclusion from the process.

Donna picks up the thread she had started, resuming her own stream of thought:

I have had that experience [of someone taking her photograph without her permission], believe you me, it's no fun! I don't want people taking pictures of me without my permission. Because I want to know what it's used for - it's my

right!"

Sam and Bob nod their heads in agreement with Donna as she continues:

"You just don't do that, you ask, because when you came you asked us if, "is it OK, I'm bringing the video camera, is it Ok if I take pictures and that, OK?" and we said it was fine...if it's just for use for your schooling, to get your Ph.D., that's fine, but if it's used for any other students in this place or any managers or supervisors in this place and it goes outside this place, well then, let me tell you something right now I'd be very angry, I'd be upset because that'll be all over the world and I don't want my picture, I don't want people to have my picture all over the world....Just to come in, have a camera, set it up, and all of a sudden you start taking pictures without people's permission! I think you make a lot of people very unhappy plus very angry and upset and I feel, I feel, very uncomfortable... You don't do things like that without people's permission.

Donna is surprisingly quiet at the start of this discussion but becomes more animated as she progresses through it. Her final statement, "You don't do things like that without people's permission", is uttered in such a way as to deride all who would think otherwise. Demonstrating an awareness of her rights, she connects her thoughts to the consent procedures used in this project, stressing that I had let them know (prior to the project's start) that they were in control over the use of any images of themselves created as part of the project. Donna admits to liking this dominion.

I, again, raise the question of why this is important to them. Bob, very animated during this entire discussion, has been finding it difficult to interject while Donna has been dominating the conversation (for her part, Donna does not appear to want to let him interrupt), but he answers me here with a caution: if someone wanted to take a photograph of my daughter, I would need to be sure and give them permission first. Taking Bob's lead, I make the distinction between my daughter (a child) and *David* (an adult), then ask them if someone else can give permission if, because of the nature or severity of their impairment, an adult cannot understand the idea of

consent or even ‘assent’, or what might happen (to themselves and others) as a result of how the image is used? Does this create a situation wherein a non-disabled person can speak for the adult with an intellectual disability? At first, they seem not to understand my question. I ask it differently, using the analogy of young children who may not understand these things and who will need their parents to make these kinds of decisions for them. This elicits an immediate and firm response from the group. Robin and Bob quickly say, "No" – it is wrong for someone else to give consent. Sam, Robin, Donna and Bob all stress that if a person is (chronologically) an adult, then s/he should not be treated as a child and “*no-one!*” can make this decision (to use their image publicly) on their behalf. Robin really does not “want to see *that* happen!”

I want them, too, to consider the question of permission if an adult with an intellectual disability cannot speak or communicate in typically understood ways. “What if *David* can't speak? Then who can give permission?” They remain steadfast - only *David* should be accorded authority over these decisions.

Ann: Would David like picture?

The group believes that David would be embarrassed at having people look, stare and gawk at this image, at a photograph that makes a spectacle of that which he has no control over – his physical body. Here, however, they unbury more personal concerns. Speaking for *David*, his (supposed) feelings about the image are revealed as empathetic expressions of their own fears of being similarly publicly presented and humiliated. Each was aghast at the thought of being so displayed. Robin was certain *David* would be “pissed off”, primarily because he was practically naked in the image. Robin’s beliefs here about *David* translate from/into his own concern to protect against the (mis)use of his own image by non-disabled others who would manipulate his

image and inflict harm. Refusing to even be videotaped for the purposes of the project, neither will Robin consent to being photographed or to use his personal photographs of himself in the work the group is producing. Controlling his image in this way, Robin feels it is better, safer, to remain outside the circulation of visual images altogether. As regards *David*, Robin was unbending - *David* would “not like to be seen naked”, and would “tell us he didn’t like it, and he found it embarrassing.” For Bob, the proof lies in his observation that *David* is not smiling – smiling is, for Bob, a sure-fire indicator of happiness, contentment, approval - it is this that demonstrates *David’s* dislike of the image. *David* has been, in fact, photographed staring off to the side (as if embarrassed?). If afforded the opportunity to have a conversation with *David*, Donna felt he would ask her “why the picture was taken without his permission”: she was convinced he might not want other people to see this picture of him because he would be “concerned about his privacy.” “You should ask first cause I may not want everyone to know, to see my picture, ‘cause it’s private.” Because she, herself, would be upset to have a picture like this taken of her, she assumes *David* would also be upset.

This conversation is hard to follow – Sam, Bob, Donna and Robin are all speaking at the same time, yet no-one seems disturbed by this (contrary to most meetings where interruptions are sometimes met with hurt feelings or angry words). Today, they are speaking in concert – talking while listening, responding without acknowledging each other. But it seems to work.

When asked what they thought *David* might say to the photographer if he was shown the picture, Sam summarily captures the group’s issues in the following fragment of the discussion, a fragment that, in the context of the larger discussion, drives their third transformation. This transformation they understand two ways: *David’s* constructed lack of power, his weightlessness (which is used to justify the lack of concern with seeking *David’s* consent) is such that in some

ways he disappears – he, himself, is not considered. In their non-indifference to *David*, to the man in the image facing them, the group claims power for *David* by removing him from the image as a means of making plain their conviction that he was not consulted, he has not consented to this.

Sam: I don't understand why you took *that* picture, this is so embarrassing, um, you had no right to do that. If you wanted to do me a favour you wouldn't, um you would appreciate my point and you should have asked before you did what you wanted to do, or so, and I would have given you my answer and you would definitely make your decision about what I say and then do what *I* please and bear with it, you know!



Sam, Donna, Bob and Robin clearly feel the weight of what they perceive to be society's blatant dismissal of them, as individuals and as members of a larger group – people with intellectual disabilities. The resultant emotional fatigue I witness in their bodies likewise pervades their work with the images. At times, I fear they can hardly bear it. Sitting (uncomfortably) alongside this fatigue, their anger equally drives the project. Aggressively, in no uncertain terms, they tell me they want someone to pay for what they have been through – they instruct me to make someone pay. Seeing risk and danger in public visual images, they nonetheless insert/assert

themselves visually into the conversation: through personal photographs they bring to, and include in, our meetings and by using photographs of themselves whose production they control. They remind me, often, that they very much like these images – personal photographs of happy people, the kind you would put in your photo album. But they make clear that public photographic images of people with intellectual disabilities, even ones that look (to them, at least) like a group of happy friends, will most likely be misinterpreted, be misunderstood, be misused – even these images are dangerous. The text, the words and labels that may accompany these representations – for example, *retarded* - must be resisted. So, too, must they fight against their dismissal by non-disabled (and more powerful) others; the simultaneous disavowal of their competence as adults (irrespective of their impairment or their ability to speak), sparks outrage and an ethical demand for the right to express themselves, to have control over decision-making in matters of their own lives. With their words, they give voice to the people in the images – it is their voice, to be sure, but one which they believe is a shared one.

*Chapter 10 – Contained, Mis/Taken, Exposed: The
Multiply Othered Disabled*

Introduction



Robin: They want to leave him there cause they think they don't know him, they think he's not, he's not wanted and stuff like that...

Sam: Right.

Robin: ...and they think he's like a terrorist or something like that, that's why they took him to, uh, what do you call it, gosh, they take him somewhere, but, they take him some, something like, other people like stabilize him and stuff like that – that is why they took him and they leave him like this, it's sad to say.

The idea of othering people with intellectual disabilities, of portraying them through photographic representation as different, distant, far removed from normative constructions, is very much Robin's issue. As the youngest member of the group, he is the one most concerned to have his adult status recognized, and to resist being infantilized and the suggestion that he cannot do for himself. Arguably the 'hippest' member (with his iPod, sunglasses, cap and clothes), Robin is also the one most 'tuned in' to television and other media, and attuned to media images of marginalized others: homeless people, refugees, the poor and displaced of Africa and other developing nations, terrorists, and victims of the 'war on terror' and other conflicts around the world. References to such come up often. While Donna, Sam and Bob are more likely to think about photographic images in relation to photo-albums, to personal memories, Robin more astutely considers them in relation to their production and circulation. (As a consequence?) he is also the most averse to being 'captured' by media: refusing to let me include him in the camera's reach when I videotape our meetings, he seems to hold the opinion that it is safer to not to have

his picture (mis)taken, not to be contained by or through photographic images, not to risk being othered by this exposure and the potential (mis)use of photographic images. Consequently, he sets himself apart – a disembodied voice on tape accompanied by, on rare occasion, the fleeting image of his hand moving in and out of the camera’s range.

Looking at the image of *David*, Robin glimpses traces of other marginalized groups: terrorists, refugees, homeless persons, and infantilized adults. As an inscriptive surface (Campbell, 1999), *David’s* body has been marked by this photographic imaging. Robin’s words (above) relay his assessment (echoed throughout his work on the project) that people with disabilities *are* erroneously regarded as different, too unlike the non-disabled populace to be known – “they think they don’t know him” – leading to a number of undesirable outcomes. Unwanted, they may (merely?) be left alone. More frightening for Robin, they may be mistakenly branded as dangerous and, thus, subject to a disciplining violence rationalized as a means of responding to, or ‘stabilizing’, a threat – a response that can, itself, be disabling, that can “leave him like this, it’s sad to say.”

Sam, Bob and Donna share Robin’s perspective and in this and the next chapter, their work shifts from the personal photo-album imaginings in the previous chapters to include a far more frightening type of ‘album’; a collection of images of at-risk/security-risk groups of people. This image of *David* (and others) is one of excess, an image that exaggerates the markers of difference. Through the taking of this image, *David* has been mis-taken. So erroneously portrayed, his true self has been stolen, un-exposed, hidden from the viewer thereby closing off the possibility of knowing. As Sam articulates, the image defines *David* as “different”, as unknowable, “challenging to understand” and beyond the limits even of their own ability to recognize or understand. Imaged and imagined this way, people with intellectual disabilities

approach, and may even move beyond, the limits of the human. Like the ‘terrorist’ (real, or in this case, assumed), public photographic representations of people with intellectual disabilities frame them in such a way as to create distance, space between disabled and non-disabled people by provoking fear in the viewer: once labelled a ‘terrorist’, for example, they are never known again as a ‘person’. Like very young infants, they are incomplete, moving toward (and thus not yet) full persons. Like the ‘refugee’, people with intellectual disabilities are both not safe and un-safe, and their exposure through media representation – as a threat they must fear – often renders them even more at risk and of being perceived as risky. Like the ‘homeless’, they are without a secure place, unwanted and consigned to the margins – unwelcome, no room is made for them. And (like terrorists, refugees, and homeless people, and, perhaps to a lesser extent, infants), people with intellectual disabilities are constantly inspected, evaluated, and judged to be different and to be lesser. In light of the group’s assessment, Robin’s response to being photographed appears quite reasonable.

The Multiplicity of Otherness



The infantilized adult.

Robin struggles with this image on many levels. He is baffled as to why the man in the image has been photographed wearing only a diaper. Insisting that the man is an adult, Robin tells me in this meeting (and many times over our months together) that this imaging of him is wrong: not

only a violation of *David's* rights (in that it was taken without his consent) and his dignity (he is naked except for the diaper), it mis-places him, leading viewers to falsely assume the man is but a child. If recognized as an adult, this identification entails a dysfunctional recognition – as a soiling and thus soiled adult. Exposing as it does his need for a diaper, the taking of this image also takes from *David* a great deal. At the time of our project, Robin is in the throes of transitioning out of child welfare services and into supported adult living. Attributing to *David* his own concern with being recognized as an adult (and his own feelings of humiliation were he to be photographed this way), Robin (and the others) laments the infantilization of *David* that he (they) reads in the image.

This concern is not restricted to the *David* image (although it assumes greater prominence here than in their work with the other images). Considering the *Tracy* image, Bob refers to the young woman in the image, and to other people with disabilities like hers, as “special kids”. Imaged as she is, in the arms of her caregiver with her wheelchair beside her, for Bob, the emphasis is on her dependency, her need to be taken care of by others as she is unable to do so herself – not yet “like us” – and this dependency is intricately connected both to her impairment and to her (resultant?) status as perpetual child.

Bob: I want to find out if there's any, uh, any staff looking out for her every day? 'cause they're special kids, what they call 'special needs', that's right, to help them out. If you need special wheelchairs, you have to, if you need special clothes – like diapers or something...

I am struck, quite often, by how common it is for Bob, Sam, Donna and, to a lesser extent, Robin, to refer to adults with physical disabilities as “kids” even when, if pressed, they readily recognize them to be chronologically adults.

Sam's take on the *Tracy* image was similar – the young woman in the image is framed in such a

way as to leave little room for any interpretation of her as anything but a young child, a baby:

Sam: That almost reminds me, that almost looks, um, the point of it that I see about it looks, uh, a little bit too, um, of a childish, um, skills, like, I mean, um, childish, uh, behaviour. Not like, not the behaviour that's inappropriate but just, um, childish age, or um, also, it also even looks a little bit immature like, for younger people, you know, like not immature in a bad way that's inappropriate but just like little kid's age, for babies, she's like a baby.

Ann: So you think that the way she looks is like a baby?

Sam: Yeah, like she [the woman holding the young woman on her lap] kind'a, um, she almost thinks to herself, it's like a baby, that she's thinking to herself it's like a baby, like a little baby, like a mother would carry her by, um, kind of, um, you know, rocking her in her hand or something but, yeah, cause that's not, um, something that's really, um, the mature thing.

For Sam, while the young woman's behavior (being held on the other woman's lap) is not, in and of itself, inappropriate, it is, however, quite immature for her and even for a much younger child. Defying as it does Sam's understanding of acceptable behaviour, it similarly does not conform to normative expectations for a person of this age - it really is only acceptable for babies. In breaking the rules, the image succeeds in othering the young woman. The consequence of this positioning is that the woman holding her (and, by extension, the viewer of the image) is thus led to an inevitable understanding of her as a baby: "she's thinking to herself it's like a baby, like a little baby" but, Sam admonishes, this is not the "mature thing". Effacing the young woman's young-adult status as it does, this is not the right way to visually represent her.

The refugee.

Robin: He looks like Africa, like poor, like that kind of thing, probably not eating enough....He's not eating enough, the food, that's what causes him to be like that.

Sam: Someone who looks like into a poor country-like situation.

Probing further, I am told by Robin that the image of this young man in the *David* image reminds him of television images of people in Africa, people displaced by war or famine; masses of hungry, frightened people wandering across the country. He is clearly troubled by these images,

by their typically spectacular features, repeating often that the people look to be “starving, or dead”. The image of *David* is similarly one of spectacle as the difference and distance between *David’s* isolated and illuminated body and that of the normative ‘able’ body has been starkly realized in this photograph. As was articulated in the chapter, *Bob’s Blanket*, the young man in this image looks to be malnourished, painfully thin. Pointing to the photograph, Robin notes that *David* looks different – his body does not have a typical shape, the malnourishment has twisted his body into “the shape of the number 7”. Sam also regards *David’s* body as different: “I mean, like, because, um, how the way, because he’s like all crippled, and then he’s like crinkled with his hands and arms and even his feet is not steady...his body length is very crooked.” Nor is there evidence in the image of material provision, of help or assistance of any kind – nothing is visible in the darkness surrounding him – the young man has nothing. These images appear to niggle at Robin, once conjured by the *David* photograph he cannot seem to let them go and tells me the same things many times. Sam re-iterates Robin’s interpretation, nodding often with a look of distress upon his face. Like the refugees on the television screen, for the group the young man in this image is at risk of harm – from exposure, from starvation – and is without a place: not welcome, he has been abandoned to the institution or to the elements; “[i]t looks like he’s outside on the ground...almost like he was in the desert or something”.

The homeless.

I asked them what, if anything, was familiar to them in the *David* image; whether there was anything in the image that reminded them of anything or of anyone they knew. Robin, Sam and Bob were clear that the photograph of *David* reminded them of homeless people – in their own country and in more impoverished countries. Robin reports the photograph “shows what it’s like” to be homeless: “the guy has no clothes, it is sad, it’s not good”. Photographed in the

diaper, with only a mattress and a blanket, they note again that *David's* body is unadorned, and his immediate environment empty – devoid of possessions or signs of material goods. Delving deeper, I ask questions to try to understand the basis of this interpretation: media knowledge or personal experience. Robin tells me again about seeing images of homeless people on television. All four relay stories of seeing homeless people; on the streets, in subway stations, outside the coffee shop where we convene before our meetings. For the four of them, homeless people are very visible, ever-present. What ensues is a lively discussion of their responses to those homeless people they encounter: although, as Robin suggests, most people “don’t care”, with some degree of paternalism they inform me that *they* care - *they* give money to them whenever they can. Determining this group of people to be far more marginalized than they themselves are, they feel a sense of responsibility and are anxious to help, to be seen (by me) as helping, and they take pride in this helping – it is a means of feeling good about themselves because they are “not-the-same”; thus both re-affirming their difference from homeless persons (in a self-affirming way), and acknowledging that because they are in a (somewhat) better economic position, they can give.

I then ask them to consider, “Where does the picture come from?” “What type of picture is it?” There is a pause before anyone answers but then Robin, Bob, Donna and Sam all speak at once, albeit in rather abbreviated terms. Sam repeated that he thought it was a “homeless picture”. I assume he means a picture of homeless people – an assumption later verified - but his choice of words strikes me as it suggests he believes the image, itself, to be without a home: it does not really ‘fit’ with or have a place in his thinking about intellectual disability or in his experience as a person with a disability. While not explicitly articulated, such a notion appears foundational to his differentiating himself from *David* and from people living on the street. This would seem to

be confirmed when, one day (outside of our meetings), Sam, Donna and Bob tell me of a person they know, a person with an intellectual disability, who “begs outside the coffee shop”. They are horrified by this, refusing to acknowledge the woman (or the reasons she may be doing this), to admit (publicly) that they know her, for fear of association. Their need to distance themselves from her is strong. This admission complicates their view of themselves as accepting of and caring for homeless people they meet on the streets and see on television. But the complexity of this fear of association is realized even more starkly in Donna’s cognizance, experience, and, indeed, pre-occupation with her own poverty – the cultural imprint of the image of *David* and of images of economically and socially impoverished homeless persons that is very much present in her own proximity to this state of being. But, at least here, she does not (or refuses to) recognize herself in the image.

At another meeting, Sam and Donna arrive before I do. Someone working in the building (and frightened by their presence – believing them to be homeless vagrants), alerts university security. Two male security officers arrive as I do – informing us of the complaint and seeking an explanation for Sam’s and Donna’s presence in the building. As we are questioned, I spy someone peering over the balcony above our heads – she slips away when she catches me looking. Donna and Sam are heartbroken at being perceived this way, hurt and outraged that the person would not have simply asked them why they were there, allowed them to state their case and prove their right to be in this space. They are extremely troubled to hear they are frightening. Having felt, until now, a sense of belonging and acceptance, they worry that others in the school see them the same way and similarly want them gone.

The terrorist.

Robin’s assessment that the image worked to mark *David* as a “terrorist”, a frightening other that

must be controlled, confined to a distant and segregated space, was echoed by Bob. Bob remarked that non-disabled others might have found *David* to be threatening, necessitating he be locked away: "Maybe he's in a cell", "The way it is set up it looks like a group home or a cell". Both regard the young man as having been mistakenly identified. Both are insistent that he has been mistreated. Robin's use of the term "stabilize[d]" is interesting and, when combined with his interpretation of the treatment afforded the young girl in the *Blatt* image, implies Robin believes *David* to have been tortured, and "left like this" – subdued, contained, no longer threatening; but also now (more?) impaired. More alarmingly, Robin suggests that the young man's and the young girl's disabilities, leading as they did to the judgment that s/he was dangerous, was the reason for the torture.



Robin was convinced that the young girl in this image, the *Blatt* image, was understood by non-disabled others as a threat. Responding to her as a real person, the group all believed the child to be incarcerated, behind bars in an institution or jail cell, incapacitated further by the straightjacket and restraint chair. Robin asserts: "She's probably, like, in a jail or something, or in prison where they're keeping her". Shifting back to the image itself, from Robin's perspective, the image paints the child "like a hostage, like a prisoner in Iraq". He repeats this many times; straight-jacketed and behind bars, it looks "like when you're a hostage", the child is "trapped" – "[i]t's like when people in the news, like in Iraq, are being tortured". What follows

is a lengthy, albeit difficult to follow, monologue on the war in Iraq, the evils of Saddam Hussein, and the torture of Hussein's enemies – Robin's struggle to make sense of stark and sensational images and reporting he sees on television. Despite the black band covering the child's eyes, he worries for this girl and for the prisoners, is concerned that their plight is made so public and embarrassed on their behalf: "It's very humiliating when you are watching that, to see that. Like why is that happening?" He would not wish his own torture and degradation (should he ever experience something similar) to be so publicly available. Sam finds this discussion almost unbearable: "Oh my God", "Oh my God, it's very depressing!" Bob finds it "very sad".

As addressed in *Weightless*, Robin believes that this young girl, like the young man photographed for the *David* image, are so tortured *because* they have intellectual disabilities:

Robin: Um, they probably don't want special people, because that's the reason why they're doing that, torture her, 'cause she, 'cause she probably has mental problems and can't be at home and they probably don't want her in that situation, to be, to be like...

Ann: Who doesn't want her in that situation?

Robin: ...to be like, like, they don't want no special people in her house, to be in that house.

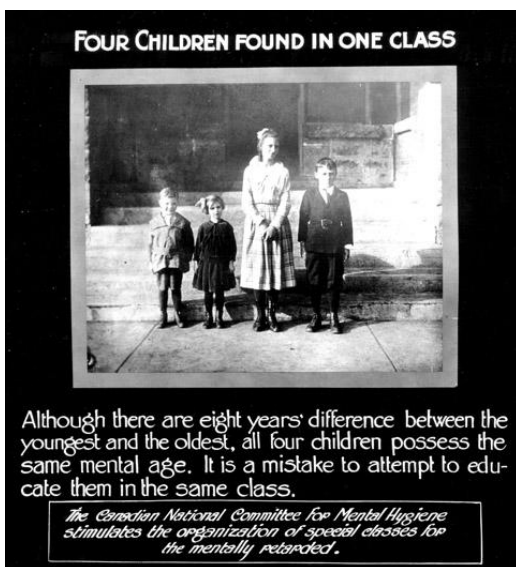
Ann: OK. Because they don't want any people with disabilities there?

Robin: Yeah, yeah, that's what she might have, that's what it shows you, that she might have.

As 'different', *David* and the young girl in the *Blatt* image illuminate for Robin, Sam, Bob and Donna how people with intellectual disabilities (at least those in public images) are both constructed and understood not to fit. Falling outside of restrictive normative constructions of human they are then marginalized by the un-disabled. Ostracized, at risk of starvation and death, they do not fit in society and, without a secure place they more closely resemble refugees and homeless people than the group's personal and preferred understanding of people with

intellectual disabilities. Yet, perhaps aware of their own tenuous place, the group members are anxious to distance themselves from people with intellectual disabilities (real and visually imagined) they encounter who, like the homeless, do not resemble (or buttress) their (hoped-for) understandings. They are fearful of the unsayable message they read in the images – “this could be me”. To be regarded as homeless, in obvious need of charity, evokes fear in each of them (arguably a realistic fear given the limited resources they have access to, their own position on the edge of poverty). In their recognition of the very pathologizing said of the images – that people with intellectual disabilities (like terrorists, refugees, the homeless) are so often perceived or determined to be frightening, a dangerous threat by un-disabled people (and their knowledge of the extreme measures utilized to control this threat) – they are keenly aware that hospitality is actively resisted or reluctantly, begrudgingly, hesitatingly (if, indeed, ever) extended. Knowing all of this, Sam, Bob, Donna and Robin, too, can read these images in the same way and resist identification with the subject/object within them.

“We Shouldn’t Be Any Different”: Educational Dis-placement and Restraints



This image is one of the last to be worked on. At this particular meeting, Robin, Bob, Donna and

Sam are quite at ease with the process and this translates into a sense of confidence, of surety in their own abilities. The meeting begins quietly enough. A long period of silence, during which they gaze carefully at the images spread out before them, is broken by Bob: looking mischievously at the others he smiles and, holding his coffee cup aloft, says, “this coffee’s keeping me awake!” Laughing, the others begin chatting about coffee and fatigue and then move to making decisions about which images to work with. Bob chooses to work on one image, Robin another. Donna and Sam both express interest in the image above. This has never occurred in our meetings and, to manage the logistics, it is decided that I will work first with Robin on his selection while Bob goes for more coffee and Sam and Donna get to work on their selection on their own. Immediately, Robin removes himself to the far corner at the back of the room, behind the camera: as a result, no part of Robin’s body (or his voice) is captured by the video camera.

Before moving to join Robin, I introduce this image to Donna and Sam. Sitting across the table from them, my back to the camera, I inform them that it was part of a mental health campaign, taken during Canada’s social hygiene era. Struggling to explain this to Sam and Donna before leaving them, I feel compelled to include the image’s text from the outset, contextualizing both image and text within the social hygiene movement’s understanding of segregation as one means of improving the genetic strength of the social stock. Walking back to Robin, I hear Sam as he starts to engage Donna in conversation about the image. As the self-designated note taker, Sam has taken on my role – asking Donna questions, he records her answers and then speaks and writes his own responses. Holding the photograph in her hands, Donna’s attention flits between the image and Sam’s face as she responds gently and seriously to his questions and then waits, patiently, as he slowly and carefully prints her answers on the sheet of paper in front of him.

When I re-join them, Sam catches me up by reading the notes he has taken. We then continue, together, the process they have begun.

Sam: [It is a picture] with an older sister, older brother, younger brother and a little sister and, also, a family of siblings who are in the same class, but they are in different ages and grades, and kids are in a special education program. It shows you it's outside of a school. They are standing outside of school and, number three, what does the picture remind you of? - it reminds me of brothers and sisters being together, and it reminds me of kids who are in school, and also kids who want to learn a lot to improve their weak areas – perfecto!

Ann: ... So, you guys think they are all in a special education class. What makes you think they are in a special education class?

Sam: The reason why they are in a special education class is because there are kids who are in different ages and grades and, most likely, they have a disability and they just wanted to learn to, ah, improve what they are, uh, having difficulties with, and understanding about other people's situations and what their concerns are.

Continuing to write as he speaks, Sam ends the last sentence of his first response in the above fragment (verbally, and with his pen and body), with a flourish – “perfecto!” In their reading of the image, Sam and Donna see a group of well-dressed (albeit, in old-fashioned garments), happy-looking siblings, standing at the base of steps into a school. They point to the four children formally lined up side-by-side in the image. Bathed in light, the children's dress is fairly plain to see. In that they are gazing directly at the camera, Sam and Donna can also see their facial expressions – some of them seeming to squint against the sun – despite the age and quality of this black and white image. Even though none of the children has a visible disability, because of the variable heights and ages of the children, Sam immediately understands them to be in a special education class. But (seeming to challenge dominant assumptions that people with intellectual disabilities are different, that they neither can nor want to learn) he points out, too, that while they likely have a disability, they still want to learn – to improve in those areas in which they struggle, and to learn about other people. Consequent to this initial interpretation, the image comes to be referred to as the “*kids in school*” image.

Ann: Do you remember that, when I told you that this picture comes from the, it is a very old picture from the 1900's, and the purpose of this picture was to tell people that if a child had a disability, was a slow learner, that they should not be in regular school - that they should be in an institution.

Sam: Instituted?

Ann: So, what this picture is saying is that all four of these of children, who are of various ages, but all four of these kids are the same when it comes to how smart they are, so, what it means is that this is a smart little girl and this is a not so smart big girl.

Sam: Yeah, that happens sometimes.

Ann: Right, so this girl and this boy [pointing to the two tallest children] should probably be taken out of this school and put into an institution.

Sam: Yeah, because the older people have to learn more but it is nice that younger people can know more than they can because they can get more intelligent or get off onto a wrong [right] start early on, to begin, but even the older kids have to know more because they are growing up, for that matter.

Ann: So, as we all grow up we still have to learn things?

Sam: That is right.

Sam and Donna both pick up on how, in this image (in vivid contrast to the *David, Tracy*, and *Blatt* images), this rather typical-looking group of children have been photographed in nice clothes, standing together in a very ordinary setting – a schoolyard. At the same time, the influence of the text is made visible in their references to the children all being in the same class – like the variability in age and height, the text seems to influence their identification of this as a special education class. However, with a nod to the ‘normality’ of human diversity, Sam takes it for granted that some children are more academically able than others, that others need extra help. He articulates that, if given the right education, the right start “early on”, young people with intellectual disabilities will know more than their older counterparts, thus suggesting it is a failure of the education system that is to blame for what people with intellectual disabilities have yet to achieve. He again dismisses the implicit sentiment that older children/people with intellectual disabilities cannot learn – as Sam notes, even as we grow older, we still have things to learn.

For the last several minutes, Donna has been sitting quietly beside Sam – sometimes looking at him, sometimes seeming to nod off as she holds her head in her hands. Drawing her back into the conversation, I seek out her thoughts:

Ann: So, do you think the answer, if all the kids are doing the same school work, but these two [pointing to the two taller children] are slow learners, do you think the answer is to put them in an institution?

Donna: *No.*

Ann: So, what do you think?

Donna: Put them in a regular school.

Sam: Yeah, to a regular school that can, like, help them improve their knowledge.

Donna: I am a slow learner. I went to a special school when I went to school with no grades.”

Sam: I went to a special school that was close to here around that time, it is almost near Spadina. I use to go the Clark Institute of Psychiatry a long time ago, when it was, I think I started when I was, for example, when I was 8 years old and I was there when I was 9 and 10 years old for three years.

Ann: Donna, do you think they [the two taller children in the image] should be in a regular class or just in a special school?

Donna: Are you saying these are adults and they don't have nothing wrong with them?

Ann: They are not adults, they are older kids, but they are slow learners, these two are very slow learners.

Donna: I am a slow learner!

Ann: Yeah, and do you say they shouldn't go to institution? Are you saying you should put them in regular school?

Donna: Yes, so they can get an education!

Ann: So, correct me if I'm wrong, you think it does not matter if they are slow learners? That all these kids should be in the same school, they should be in regular school?

Donna: Yeah. I don't think they should be any different, we shouldn't be any different!

Sam: No. there should be no difference for that.

Neither the availability of the text (in this image it is quite prominent - the caption is bold-face white lettering, starkly foreground against a black background) nor my initial contextualization of the image would seem to have been sufficient to ensure Sam's and Donna's understanding of the implicit message of the text – children with disabilities must be excluded from mainstream

educational settings and placed, instead, in segregated ones – and it is only when I explicitly draw them to it that either one reacts. As was articulated in the chapter, *Bob's Blanket*, Donna has some familiarity with institutions. She reacts quickly and strongly to my question, opposing the strategy of removing children with intellectual disabilities from regular schools and educating them, instead, in institutions. Looking at Sam, her voice rising – she stamps herself a ‘slow learner’. In fact, she does so twice in this exchange – each time with a bit more vehemence (or is it defiance?). Denouncing institutions as educational settings, Donna explains that children with intellectual disabilities must attend regular schools “so they can get an education!” From her perspective, children with intellectual disabilities should not be treated any differently, or understood to be different – she then includes herself here: “we shouldn’t be any different!” Sam concurs. While not claiming the label, “slow learner”, Sam appears to similarly identify as such (articulating his own placement as a child in a special education setting), but to do so with some discomfort or reluctance. Whereas, till now, he has been speaking directly to me, holding my gaze in his, at this point he breaks this connection; seeming to avoid my eyes he looks off to my right as he tells me of this time in his childhood.

Ann: Did you like being in the special ed. class? Or would you have rather been in a regular class?

Sam: Well, I’d would rather be in a regular class but, just for starters, in a special ed. class to help me improve uh, what’s it called, my learning disabilities or my knowledge or something, um, for that matter, um, but afterwards I would like to have a more of a change to be more of a regular practical program, that’s more high classified and more like, um, a mature program because if you are always, like, into a low modified program that is almost about, like, learning about, um, little kids’ stuff, you know, because we’re all grown up, we don’t want to learn anything that’s like, um, like a baby learning or education, cause that’s not the way to, there’s nowhere to go from there, you know. But if you are in high classified, then that is the way to get started to your, um, more refreshing, more appropriate career. It helps you for your career and goals and future now, etc.

Ann: What about you, Donna, you were in special ed. Did you want to be there or would you rather have been in a regular class?

Donna: I would have rather wanted to be a regular class.

Sam: I agree.

Donna: I did not want to be in special ed. I did not want to be in a special ed school.

Sam: Exactly, and I feel, like, very embarrassed and that like, whenever I'm in a, like, a regular class and learning some kind of a program and then some kind of a, like, tutor is right beside me and trying to, what's it called, give me, like, a support. I would rather have the support from the teacher and not like learning, like being treated like a child because I'm really, like, grown up and more older and independent. I don't need people watching me like a little kid or treat me like I'm a puppy on a leash, you know. That's something I really don't appreciate. Yeah, me and my friends who are in the CICE program at Humber College didn't like any of this so we would prefer to go to a, a more regular program instead! In the future, once we go back to school, rather than taking some kind of a special, a special class, or a specialized program.

Ann: Alright, I'm glad you are telling me this stuff. Let me ask you a question: What if you were in a regular program and the teacher wasn't able to help you enough, and you were not getting the work done - how do you think it should be handled?

Sam: Well, as a matter of fact then, what you could do at your own time is, like, speak to the teacher about, um, something that you, um, kind of misunderstood about, um, what he wanted us to do and also the homework: how does he want the stuff to be completed and what, um, he needed to be assigned for due dates or anything like that, for any works that has to be done, or written out or anything. It's always good to mark things down and that's the way to get things done appropriately on the right, on the right track and on the right side of hand.

In the safety of our research group, Sam does not hide having an impairment: as noted, he is not quick to embrace the label 'intellectually disabled' but he is well aware that he sometimes needs support. For Sam, it may be acceptable to receive special education support, but *only* when you are very young, "just for starters". He believes this would be enough to then permit students with intellectual disabilities to be included in regular classes. Gazing steadily at me, he tells me that this is very important as being in a "low modified program" serves only to infantilize and restrain people with intellectual disabilities by teaching them "little kids' stuff", even when they are grown up. Shaking his head, he states that this "baby learning" is of no value, it doesn't teach you anything – the upshot being there is "nowhere to go from here". Not only that, it is also extremely embarrassing!

Scowling as he speaks, Sam talks of his experience of having a “tutor” (an educational assistant) imposed upon him in the regular classroom. He understands the tutor’s role is to support him, yet he is not comfortable with being so tethered. Erasing any pretence of privacy, the exposure accruing from the presence of the tutor singles him out, marks him as different, as needing help. For Sam, it results in his being perceived and treated “like a child”, “like a little kid”, and (even more dehumanizing) “like I’m a puppy on a leash”. Recalling these incidents, even now his body stiffens, registering his visceral reaction to this very public humiliation. I can see, and almost feel, his mix of anger and shame, though his voice rises only imperceptibly, and his body does not move. He knows very well that he may require help with certain things, yet Sam wants this need handled in a more typical, ‘normal’ manner – the way it is provided to non-labelled children – discreetly, by the teacher, outside of class time. This image, on its own, does not include any such markers of difference (ordinary looking children on the steps of an ordinary looking school) and, without the addition of text, Sam and Donna do not immediately see disability contained within it. Whereas the *David*, *Blatt*, and *Tracy* images, with their many markers of disability, exaggerate difference, this one does not, *on its own*, make difference and need public. Without this exposure, these visible signs of intellectual disability, it does not (as Robin notes elsewhere) wound. The text, however, does wound: altering the un-disabled viewer’s reading of the image, segregation is now understood to be best.

Inside and outside of this and other meetings, Sam and Donna speak often and disparagingly about their experiences in special education programs. Expressing worry over “their academics...the amount of average levels, amount average levels of how they learn”, Sam despairs that children in special education are not given what they require to keep pace. Her anger and resentment audible, Donna feels she learned nothing in these programs, programs that

did not even have grade levels: “I was not getting enough education in the special ed. class. They were not spending much time with me.” This has cost her dearly as she is now excluded from post-secondary educational opportunities. Donna wishes she could have earned a high school diploma and then attended college or university – with much sadness, she asks me often about the educational background of current social work students she encounters in the university building in which we meet. She feels herself to have been deprived of these opportunities and bemoans the fact she will never truly belong in this space, nor be able to identify herself as a ‘graduate’.

I ask Sam if he agrees or disagrees with the image’s caption – that it is a mistake to have children of the same ‘mental age’ in the same classroom. He agrees with this message – it is a mistake for them to be in the same classroom – but for a different reason than that articulated by followers of the social hygiene movement: to do so brands the children “handicapped” (as the ideology behind the caption no doubt intended) but, for Sam, placement in a classroom other than that appropriate to one’s chronological age might (more alarmingly) actually serve to disable them, to create the “mental disability” that is then used misanthropically to justify a more segregated placement.

Although there are eight years' difference between the youngest and the oldest, all four children possess the same mental age. It is a mistake to attempt to educate them in the same class.

Sam: Well, it would be much better if they were in the same classroom because of their age. Because they would obviously get on the right track and people would not, honestly, have some kind of a mental disability that does not know exactly how to keep focused onto the right track whenever people are trying to get knowledge inside their mind. If people are in the wrong grade and age or so, they could be considered as something like handicapped.

Ann: So if they put the big kids in with the little kids these kids would look handicapped?

Sam: Yeah, technically.

Ann: Do you agree with that, Donna?

Donna: Yup.

I am, at first, surprised by their answers to my next question:

Ann: You know the question that is sometimes hard to answer, “if somebody does not have a disability is looking at this picture, what do you think it tells them about people with disabilities - something good or something not too good about people with disabilities?”

Sam: It would tell them something good about the people with disabilities.

Ann: What would it tell them?

Sam: Well, what it would say is they are kids found in one class and, also, they really want to get their educations completed, and they want to look into something smart, and once they are learning, because they are trying to finish their education effectively, all they just do is that they just would be capable to learn how to improve what mistakes are to be dealt with and, also, to make things even better.

Talking with Sam, he tells me that people with intellectual disabilities *want* to be in school, they *want* to be educated, they *want* to learn, and they *want* to be recognized and represented as being “smart”, being capable of learning. Sam makes no secret of his own need to be viewed this way. Education is critical to “making things [their lives] even better.” In this regard, people with intellectual disabilities differ little from their non-disabled counterparts. Consequently, this image, of children looking well-cared for and happy, standing outside of what appears to be a typical or ‘normal’ school building, is not at all offensive – it would tell the non-disabled reader of the image a good story about people with intellectual disabilities. Pursuing this further with Sam and Donna, I learn that it is the text that is problematic. Concurring with the text’s more overt instruction (that having different “mental ages” demands “different” treatment) Sam and Donna oppose its subtext - that such differences justify segregation of any sort. Instead, they articulate the necessity of individually tailored educational programs *within* regular, typical, or normal classroom settings. Acknowledging the exigency of attention to difference, they simultaneously resist a response to this difference that works in any way to stigmatize or to other

people with intellectual disabilities.

Ann: Now, would you change this picture?

Sam: Um, no, I would keep it the way it is.

Ann: Donna, would you change it?

Donna: Change the picture?

Ann: Yeah, would you change it?

Donna: I would change the words out of it. Yeah, I think I would take the words out.

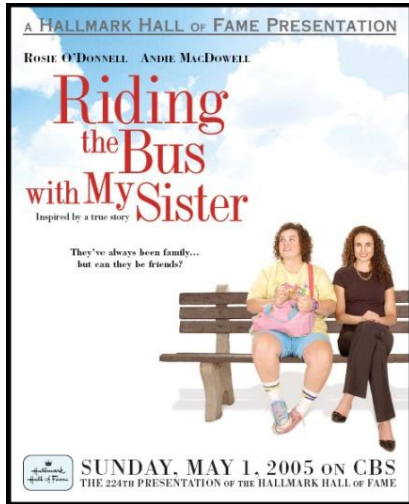
Holding the image up while reading the words again, quietly, Donna tells me she wants not to alter the image, but only to change the words, to re-caption it. She and Sam tell me this will transform the message in a manner that will be more just, and more in keeping with what they believe to be fair and true, one that makes room for other meanings to take hold.



What is highlighted by Sam and Donna are the many ways that the education system (and images of such) works to other people with intellectual disabilities. Labelling them as different *and* as lesser, they are consequently treated differently, socially and spatially excluded. Seeking to belong, they are instead dis/dys-placed - at times segregated and kept separate from typical educational settings, at other times separated (physically and via their identification as different)

from typically-developing children even within the same classroom. Inspected and, through these placements, highly inspectable, they are infantilized, judged to be uneducable; consequently, they are un-educated: what they receive, how and where they receive it, is both different and less (in quantity and quality) than what their non-disabled counterparts are offered. The system disables them: restricting the opportunities afforded them, people with intellectual disabilities are restrained (even, at times, contained), held back, unable to develop or grow or learn despite their need, desire, and ability to do so. Their concern with being so dis-abled, restrained and contained, symbolically and metaphorically links back to the *David, Tracy*, and *Blatt* images and parallels the effects of public photographic imaging of persons with intellectual disabilities. Grappling with the (staged) placement of people with intellectual disabilities in the *David and Tracy* images, as contrasted with the (differently staged) space occupied by the children in this visual image (yet confirmed by the text of this image when viewed as a whole), they are recognizing that such dys-placement occurs in photographic imagery as well. The inspection inherent in, and inspectability of, public photographic images; what is stolen or lost in the creation, the (mis)taking of photographic images; and the im/possibility of visual exposure – of the ‘truth’ about disability as contained within public photographic images – have become more urgent issues for them.

(Self)Vigilance: “People Will Be Looking At You”



This image, a movie poster, sparks excitement within the group. Not one of the group members has seen either the movie or the poster before. They are very pleased to discover another film about intellectual disability and we spend about a quarter of an hour talking about different movies we have seen that deal with intellectual disability. Seldom straying into the terrain of critique, the discussion, instead, seems to celebrate the (from their perspective) rare instances in which intellectual disability makes it to Hollywood. Perhaps this is what leads to their request for the full text before beginning work with it.

Ann: What do you see?

Robin: A bench, and she's sitting down and she's thinking in her mind, dreaming about something in her mind, be she has no, she's pretending to be, like, to, like, have a mental challenge or whatever, so she's trying to think, like, she's going like this [demonstrating staring off into space], moving her hands, twitching.

Ann: Because that's part of pretending?

Robin: Yes, yes.

This image is a colour one. In bold red lettering, the large text has been placed upon a background of blue sky and white clouds. Two women, one in bright clothing, sit together on a bench. The colourfully dressed woman they recognize immediately as the actress Rosie O'Donnell. Asked what they see when they look at this image, Donna and Bob both see happy

people (both women have broad smiles, easily seen), content with each other's company. For Sam, the image makes him feel "fine". Bob really likes that the text, "the words", are "big" – he has problems with his vision and appreciates large text. Robin is drawn first to the bench that the women are sitting upon. Its central placement in the image seems to invite his eye towards this detail but he then moves beyond it to the one woman who has been photographed looking up and off to the side, to question (what he later terms) *Rosie's* "dreamy look", a look he regards as evidence that she is not disabled, that she is only pretending to be so. He notes, too, *Rosie* appears to be making her hands twitch, again as part of imitating a person with an intellectual disability. (Both are in contrast to the staging of the second woman – composed, still, gazing steadily and confidently at the camera.) Picking up on this thread, I point to the clothes the two women in the image are wearing and ask the group to talk more about their appearance. To my eye, the women have been photographed as contrasts; their poses, body language, facial expressions and gestures, and wardrobes differ significantly. Speaking to the functionality of their clothing, Robin speaks first, stating that the one character looks to be dressed for business in her very professional and conservative outfit. The purpose of the *Rosie* character's wardrobe – a fanciful mish-mash of colours, very informal - is less clear-cut. Robin hypothesizes as to why she might be dressed as she is – maybe she is off to play soccer or baseball, maybe to the beach in Florida. His musings precipitate a discussion (one which will surface again) on the importance of clothes, of dress and appearance, to non-disabled responses to people labelled intellectually disabled.



Ann: Now, if you see somebody, this I wonder about a little bit, if, if you see people with disabilities, do you think it's important how they dress, do you think it's important what people with disabilities wear?

Bob: Yes, because people will be looking at you.

Robin: People are gonna be watching why you dress like that. And that's why when you're going something like a, like, like a place, like something, they tell you what you have to dress up for this, and you have to dress what they tell you, so people are gonna look at you "Why's this guy dressing like that?", "You can't [be] dressing like [that] – for business. Business, business people they won't let you in, you know. That's how people are - you have to dress for the business.

Quickly and assertively, Bob lets it be known that appearance is important because, as a person with an intellectual disability, people will be looking at you. Robin seems to agree yet (at least here) narrows his definition of those people who might be looking to a single category – “business people” (who possess the power to determine whether or not you get – or keep - a job). Robin has a paid job and this, in addition to being socially and economically advantageous for a person with a disability, is a source of much pride (I am reminded of Bob's comment that the people in the *United Way* image – nicely dressed people – had jobs, and of how important this was to him). Robin tells us that he must wear a uniform to work and I get the sense that, as part of his employment training he has been drilled by his employers (and others? his social worker?) on the importance of wearing clothes appropriate to the task, to the place. Acceptance and inclusion hinge upon the correctness of one's apparel: “You can't [be] dressing like [that] – for

business. Business, business people they won't let you in, you know. That's how people are - you have to dress for the business." While the woman on the right would clearly meet these criteria, the *Rosie* character would not. Robin is very matter-of-fact' as he imparts his thoughts here.



Ann: So, you have to dress the right way, depending on where you're going?

Robin: Yeah. You have to dress where you're going...

Ann: Alright.

Sam: Yeah, so other people don't like, uh, kinda, look at you into...

Robin: They will look at you, they will, they will look at you *for sure!*

Ann: Yeah?

Sam: ...some kind of like, weird way or thinking 'why is that person', 'that person's not wearing the right kind of clothes' or anything...

Robin: They will look at you for sure 'cause that's how they are, that's how people are. They will look at you for sure.

Sam: ...and then how you would feel inside is like, kinda like, yeah, or you don't feel humiliated or you know what I mean?

Robin: They're *all* gonna look at you, *for sure*, saying 'yo', why does this guy dress like that?

Ann: OK, alright.

Robin: That's how people are.

Ann: So, you think, Sam, that it is important, otherwise people will look at you like you're, give you funny looks kinda' thing?

Sam: Yeah, or like weird looks, or glaring, or whatever.

Robin: They just don't want you here, they're just watching, they don't want you here, that's why they're gonna look at you.

As Robin speaks, one of the other group members (caught on camera) shakes his/her head, smirks and, trying to make eye contact with the other members, roll his/her eyes in a manner that seems to belittle Robin. At another meeting Robin was late, a situation exacerbated by our being in a different room and his difficulty in locating us. This same person uses the opportunity presented by Robin's lateness to complain about Robin – citing his music, his behaviour, his clothes and his swagger as a problem for him/her. S/he attributes these difficult (for him/her) aspects of Robin's character to the fact of his being black and states s/he does not like black people. The other group members look uncomfortable and I initiate a discussion about respect and how racism does not have a place in the group – the other group members nod in agreement as I speak. The speaker tries first to defend him/herself, and then retorts that we do not like him/her and are taking Robin's side. As we work through this, Robin arrives. Angry and agitated, he accuses us of deliberately not letting him know where we were but we are able to resolve this and the meeting progresses without further incident.

Sam and Robin speak both to and over each other here. Quite remarkably, they are speaking at the same time yet seem to be hearing and responding to each other as they do. With some difficulty I struggle to follow them both, and I think that, perhaps, they just understand the situation the same way. Robin and Sam share an expectation that, as people with intellectual disabilities, they will be looked at – “they will look at you *for sure!*” This is not a neutral look but is, instead, staring – the able-bodied gaze intensified; a “weird way” of looking or viewing particular to people with disabilities that frames and fixes the disabled body as “an icon of difference” (Garland Thomson, 1997:26). The punctuated rhythm of Robin's speech reflects the insistence of his message; again and again he tells me that *people-will-look*. I am, by now, very well aware that Robin, Sam, Donna and Bob have extensive experience with being stared at, with being singled out because of their disabilities, the particular features and traits that un-disabled people attend to. Spoken from his position beyond the borders of the camera's frame, Robin's comments have an element of hopelessness; non-disabled others will stare at you “‘cause that's how they are, that's how people are.” The stares are an inevitable fact of his daily existence, to be managed, deflected, resisted, or (much harder for the group) renounced (Garland Thomson, 1997). Moving well beyond curiosity, these stares do not signal indifference for they are evaluative: measuring the person with an intellectual disability who is not properly dressed, non-

disabled people judge him or her to be different, insufficient, outside the perimeter of ‘normal’. With a pained expression, Sam entreats me towards empathy, he wants me to put myself in his situation and consider how I might feel to be so constantly inspected and judged. Belittled and humiliated by this extreme ableist gaze, Robin and Sam are anxious to avoid it. Watched by non-disabled others, these looks and stares are thought, by Robin, to derive from, and unequivocally convey, a rejection of people with intellectual disabilities, a rejection of *him*: “They just don’t want you here, they’re just watching, they don’t want you here, that’s why they’re gonna look at you.” This inspection, this unceasing and intentional surveillance (they will stare at you until you finally go away) frightens them and forces Robin and Sam to govern themselves, to carefully attend to their dress and their appearance, to offset or diminish the staring. They tell me it is important not to draw undue attention to oneself, to look ‘normal’ and not stand out – to pass. Failing to do so (as *Rosie* does in this image) means relegation to such segregated spaces as those inhabited by *David*, *Tracy*, and the child in the *Blatt* image.

Robin is quite fashionably dressed whenever I see him (although never outrageously so). He will ask me often if I like his clothes. Preening a bit, pointing out the details, he will tell me about shopping for them, and the look he feels he has achieved. By contrast, Sam, although always neat and tidy, consistently wears rather conservative and understated clothing.

For the most part, Donna and Robin are on the same page, but Donna has far less faith in the power of clothes and appearance, in Robin’s strategy to blend in; to try to look and pass for ‘normal’.

Ann: Do you think that’s true, Donna? That if you’re a person with a disability and maybe don’t dress like everyone else – do you think people look at you?

Donna: (pause) Yeah, they might look at you funny, and if you dress, um, funny they might make fun of you. If you, um, well, they make fun of you regardless of whether, how you dress or not, they still make fun of you...

Ann: Do you think they...

Donna 'cause, 'cause I know they make fun of my and I, I, *I'm* dressed properly and then, and, and, and they make fun of me, so, I don't see any difference...

Ann: OK.

Donna: ...like people on the street, um, or anybody, for any matter, people that I know, it doesn't matter, I'm not gonna get into details 'cause, just, uh, uh, uh, there's certain people that I know, you know, um, that uh, you know it doesn't matter how you dress – they're gonna make fun of you no matter what, it doesn't matter how you dress, they're gonna make fun of you, 'cause, 'cause it doesn't matter how I dress and they make fun of me, I mean, so, so no matter what, regardless!

Robin: Unless you dress properly, then they won't do it. It depends how you dress, that's why they look at you and think you don't – you dress for the situation.

Bob: See, it's just like when people look at my chin, my funny chin. They think it's funny - it's not. It's just something they're noticing.

Ann: OK, so people stare at your chin?

Bob: And sometimes they make of me cause I have this, but I try not to pay no attention to it.

Speaking to her sense of the inevitability of the stares, Donna expects not only to be stared at, but to be stared at irrespective of what she wears or, for that matter, does or does not do. Speaking with much emotion, her hands covering much of her face as if trying to hide, Donna's conviction is rooted, once again, in personal experience, in her history of being looked at, teased, ostracized, and in her surety that she is powerless to prevent this. The stares are hurtful; the accompanying behaviour (teasing, being made fun of) is hurtful. As Bob notes, people without disabilities will pick up on certain features, such as his "funny chin" and refuse to see anything else – 'Bob' (the complete and complex collection of pieces that are the sum of Bob) becomes invisible, erased, reduced to this particular visible aspect and thus unknown. But for Robin, the notion that clothes *can* make a difference sticks like a burr. He patiently lets Donna speak but then quietly, albeit determinedly, re-asserts his opinion.

By now, everyone is talking at once – talking to everyone, but sometimes to no-one in particular: this is unusual, unfamiliar. It is even harder to sift through what is being said. Sam and Bob seem to be repeating what Robin said (that clothes *are* important) *and* what Donna said (but that they *won't* make that much difference, overall). Bob introduces the idea that what matters more is relationship: quickly sitting up and forward in his chair, he begins to gently, but rapidly, stroke his (offending) chin and recounts again how strangers who see him on the street often stare at and make fun of his “funny chin”. Gazing directly at me, he then goes on to say that people at his workplace, people who know and like him, don't do this – they neither stare at nor make fun of him. Nodding his head rapidly, his body language makes plain that this is important to him. Perhaps having picked up on this, Sam begins to talk of how his colleagues at work – again, colleagues who have come to know him – treat him “pretty good” and that it is “important to be treated with respect at work”. This assessment derives from his experiences at a previous work placement where he felt ostracized and mistreated by other staff persons who neither knew him nor understood his disability. Sam felt the other staff treated him too harshly and meanly and he was disappointed in them. His upset is visible. At the same time, Robin speaks at length of his experiences of being badly treated at work, of being singled out because of his disability. Turning his attention from Robin and I to Sam (leaving Robin still speaking), Bob gently commiserates with and supports Sam and the two of them share an animated discussion of their experiences with non-disabled staff persons in their various work placements.

Reminding them the image was part of a movie poster, I asked them what non-disabled people viewing this poster might think the movie was about. Sam believes the image infantilizes the *Rosie* character – this is the message non-disabled viewers would take from the poster:



Sam: That she's [the second woman in the image] treating the adult, like, she's honestly a child.

Ann: But, but, kind of like treating her like a child?

Sam: Um, almost, but in a good way, not like in a critical way or anything.

Ann: Explain to me, what's a good way?

Sam: Well, I mean, just to, like, um, give her some caring and also with, uh, support, and also with, um, justice, and, uh, diversity, and just, uh, giving the person peace and freedom, and uh, showing them some kind of, uh, a sweet caring, um, tone and, uh, attitude.

Ann: OK, and what would be a 'critical way'? What would you mean by that?

Sam: Well, a critical way would obviously be, um, torturing the child,...

Ann: OK.

Sam: ...and just, um, being pushy or bossy, and, um, ordering the person around, like causing her stress or, uh, kind of like, for example, um, like I would say, is this, like maybe keep always holding onto her hand the whole time, not letting her have the, what's it called, um, the peace for herself to be, um, like, what's it called, independent without holding her on a leash or anything, I mean, it's almost like walking a dog on a leash or whatever.

Ann: OK, and that's a critical way of treating someone like a child?

Sam: Yeah.

I am struck in this meeting by his articulation of how non-disabled others 'critically' infantilize people with intellectual disabilities – a dehumanizing and controlling process equivalent to torture. These ideas echo his work with many of the images. Pursuing this with Sam, I am able to clarify that, for him, this image does *not* show a "critical" infantilizing of the *Rosie* character – it is understood by Sam to be a more "optimistic" way of treating her like a child: a caring for her

and watching out for her safety that is, in part, a function of her having a disability. In this sense, babying *Rosie* is not a “bad” thing – it is, in fact, very respectful and stems from love. I am surprised by this as it appears to contradict his earlier comments regarding the infantilization of *David* and of *Tracy*– in both cases the posing of the people in the images as people needing (and, in the instance of *Tracy* receiving) care in ways similar to that required and afforded (without judgment) to much younger children was deemed an act of violence against them. Unlike *Rosie*, *David* and the young woman in the *Tracy* image are, by Sam, denied respect of this different way of being. But he confounds and complicates this yet again when, soon after, he shares with me his concerns over *Rosie*’s footwear. Sam is especially perturbed by *Rosie* photographed as wearing mismatched shoes:

Sam: Um, actually, no, um, it would be nice if it was just only, like, um, a white running shoes, rather than having, like, a, a two colours of shoes, ‘cause that’s usually for like, kids or whatever, but a lot of older gal people they usually wear those, like, two colour shoes and it’s kind of funny.

Shifting gears to now oppose the kind of infantilization of *Rosie* that results from her footwear, Sam returns to the connection between appearance and a judgmental stare. He observes *Rosie*’s shoes might be tolerable for a child but not for an adult, thus distinguishing *Rosie* from a child. Revealing his certainty that particular dress codes apply to different age groups, Sam further differentiates *Rosie* (and himself?) from another (marginalized) segment of the population here; from those “older gal people” who “usually wear those, like, two colour shoes”, even though they look “kind of funny.”



Asking the rest of the group if they felt the image made *Rosie* look like a child, there was unanimous agreement. With Sam's earlier articulation of infantilization as 'good care' in mind, I ask them if making *Rosie* look like a child is a "good thing": they again respond unanimously – this is *not* a good thing. In answer to my question, "Why not?" they tell me it is because the image is not then a "true" representation of people with intellectual disabilities. They inform me they know *no-one* with an intellectual disability who would dress like this. Robin said such people might exist, somewhere else, but he doesn't know them. I wondered how they might respond to someone with an intellectual disability whom they *did* know, should s/he decide to dress this way – "would you say something or leave it to them?" Robin tells me he would "leave it alone", simply "walk away" (again, he assuredly repeats this idea several times). Speaking to me, he disregards the others' attempts to answer the question and, even as they try to speak over him, carries on, stating that he would not interfere in someone else's business, that he is content to "do his own thing" and leave other people to take care of themselves. It seems important that I understand he would not particularly *want* to be associated with people with intellectual disabilities who dressed inappropriately. As noted elsewhere, appearance is of particular importance to Robin, as is his status as someone who works, and it is clear he would much prefer to identify with (and be identified as being similar to) the more professionally dressed "business" woman sitting beside *Rosie*. Bob, too, would walk away. Sam said he might talk to the person, but *only* if s/he was a good friend. In this instance he would want to discreetly and helpfully give

the person advice so as to make sure they were not embarrassed (though I sense he, too, would be mortified to be caught by others in the company of someone so radically not conforming). If not a friend, he might talk to their staff person or “maybe the leader of the self-advocates’ group” and ask that person to intervene. Donna was, interestingly, non-committal on this topic.

As they continue to work with the image, we return to Robin’s observation that the actress, Rosie O’Donnell, is not herself intellectually disabled but merely pretending to be. I ask them whether they, and other people with intellectual disabilities, are in agreement with non-disabled actors playing intellectually disabled characters. At first, Robin remarks that, in his opinion, this is acceptable but *only* if the actor sought the permission of people with intellectual disabilities and then conferred with people with intellectual disabilities about her portrayal to “make sure she gets it right”. “If they’re not doing the right thing it could be the wrong image so she has to make sure she’s doing it right, in the right image...so she won’t mess up the whole concept.” Sam was far more nonchalant in his response: “Well, obviously it doesn’t make any difference, you know, because it’s only an act, it’s only a movie that they’re just showing.” Bob jumps in to remind Sam, “But they still have to get permission! To see if it’s OK or not!” Deviating from the others, Donna passionately disagrees:

Donna: They’d probably be upset...well, if Rosie O’Donnell, I mean, she she doesn’t have a disability so therefore she shouldn’t be acting it out like that because I don’t think that’s right. I don’t think if you, you shouldn’t be something that you’re not ‘cause, uh, that’s not right. You shouldn’t be something that you’re not. I mean it’s different if you, if you’re born with it and you have this problem all your life, that’s a different story, but she doesn’t, she’s not, she doesn’t, um, she doesn’t have a disability so I think it’s totally wrong...

Ann: OK.

Donna: ...I don’t think she, she should be acting out something like that that she’s really not, that she wasn’t really born with. That’s the way I feel. I don’t know about anybody else, but that’s the way I feel! Well if I wasn’t born with a disability and I started acting out like that, people would think, you know, ‘what

kind of a, what kind of a person is this?’ acting out something that she’s really not.

And later:

Because she wasn’t born with a disability and I don’t think that, I know it’s a movie but I don’t think she should be acting like that.

Robin: “She shouldn’t be acting like that and that’s the truth.

Anger and bitterness underlining her words, Donna is firm in her position that one must act in accordance with one’s station: if not disabled, then you are not allowed to pretend you are.

Talking with her about this, I get the sense she feels that without the lived experience of the “problem” of disability, one has not earned the right to feign disability – to other yourself – irrespective of the purpose. In this regard, only actors with disabilities should/could (convincingly) play these roles. Her comments hearken back to her doubts about the unlikelihood that people with intellectual disabilities would be permitted to pass for normal, hinting at notions of fairness and reciprocity as she practically spits out her words: “‘what kind of a, what kind of a person is this?’ acting out something that she’s really not.” They return us to consideration of the different staging of the two women: *Rosie* with her “twitching” hands, unconventional clothing, child-like and dreamy look; the other woman sitting more demurely, more controlled and contained within her professional and very adult clothes. *Rosie* is determined not to have been successful in her attempts to portray a person with an intellectual disability. Donna’s arguments prove sufficient to sway Robin to her side in this debate.

Directing them to consider how they might change the image, they tell me that what is most important is to change *Rosie*’s clothes – “it has to be changed” - to have her dressed in “more adult clothes”. One after the other, they tell me to “change it!” Robin makes short work of what needs to happen:

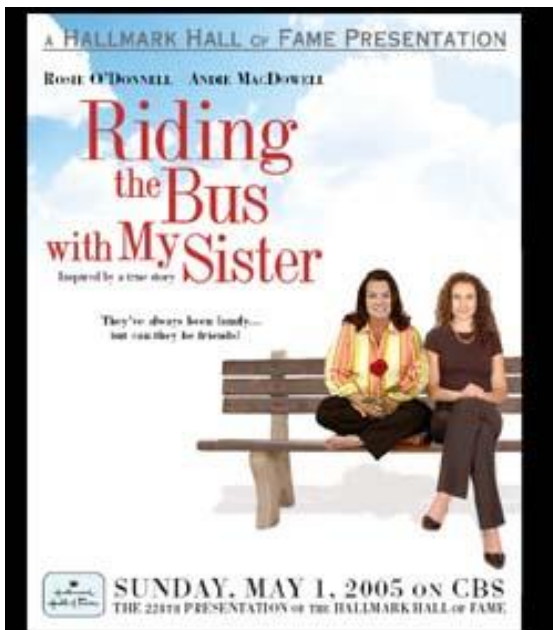
The shorts has, have to go. The t-shirt has to go. The bag has to go. The shoes, the shoes has to go. And the socks has to go.

Robin and Sam want her dressed in clothes much like my own on this day – jeans and a turtleneck sweater and single colour running shoes (this is a must!). Bob suggests a pantsuit whereas Donna thinks a “nice dress and a nice jacket” (clothes Donna, herself, favours) would be ideal. Robin is insistent: the big pink bag must also go.



I remind Robin of his first impression of *Rosie* in this image – that she had a “dreamy” look on her face, and that she might be dreaming about acting like a person with a disability. Robin is quick to say this aspect of the image should also be changed – it is important to have *Rosie* looking straight ahead, directly into the camera as the other woman in the image does – that’s what you do in film posters. (Interestingly, *David* and *Tracy* are similarly looking off to the side, away from the camera – albeit, not with *Rosie*’s “dreamy” look – and the child in the *Blatt* image is prevented, by the black band from looking at the camera, from returning the gaze: neither Robin, Sam, Donna or Bob pick up on this.) Robin hates the dreamy look and, like Sam, Bob and Donna, he does not know anyone with an intellectual disability who has this faraway look on their face. Sam points out that *Rosie*’s body language and clothing in the image suggests some kind of disability, but that she does not have an obvious disability “that shows on her face”. Pressing him to elaborate, he means a disability such as Down syndrome, one that is immediately recognizable to the non-disabled viewer. He believes that *Rosie* has been photographed this way

to suggest intellectual disability; this dreamy look is an intentional ploy to mark her as intellectually disabled, but he and Robin strongly disagree with this. Separating *Rosie* the actress from the character she plays in the film, Robin, like Donna, asserts that because Rosie O'Donnell does not have a disability, she should not be made to look like she does. With Ted's assistance, they go on-line and view other scenes, other photographic representations of *Rosie* to select one which they believe will better work here. They select an image that has *Rosie* dressed more like the other woman seated on the bench in the movie poster: both are wearing more professional clothing. With her face, eyes and body facing forward, she (again, like the other woman) gazes directly at the camera, an alert and attentive expression on her face. Her body is now less open, more composed and controlled – again, more like that of the other woman in the image. The stark contrast between the two has been alleviated by the change, their differences eradicated and, as a result, not only has *Rosie* been re-imagined but the other woman now looks less formal. The transformation to *Rosie* serves to equalize, to reduce the distance between them. For the group, this is much more suitable.



What the group concludes from their work with the *Rosie* image is that this image works to other people with intellectual disabilities: the choices made as to how intellectual disability was represented in this movie poster invite looking, invite staring, but not knowing, not welcoming. Such looking is regarded by the group as inevitable for people with intellectual disabilities: “People will be looking at you.” “They will look at you for sure.” That’s just how (non-disabled) people are. There is some disagreement amongst the group members as to whether they have any power to prevent this looking but no dissention as regards their understanding of these looks as evaluative, judgmental. These are looks that guarantee they know they are unwanted; a type of inspection that renders them ‘different’ and, in pushing them out of the category ‘normal’, effaces their personhood and consigns them to the margins while simultaneously un-disabling those without the marks of disability, those who are assigned, instead, to the more privileged space of the normal. They recognize, too, the reductive inflexibility of this categorical looking – unlike non-disabled others who can, at will, pretend to insert themselves into these margins, movement across this divide is made more difficult, if not actually blocked, for people with intellectual disabilities. The group’s words lay bare their desire to cross this line, to pass for “normal”, and the lengths to which they will go to do so. The group’s cognizance of the power of this looking and their strong wish to avoid it dishearteningly leads them to consider similarly othering those people with intellectual disabilities (even their own friends) who may not conform to normative ways of dressing.

Mis-placed and Re-placed: (Dismantling) the Infantilization of David



Returning to the group's work with *David*, let me begin with one of Sam's interpretations of the image:

Well, it's just only a kid who's just a very, very mentally disabled, who has a mental disabled and, uh, also he just, um, he's, he's just has like a poor habit of a situation that he hasn't been eating, um, like for over like a couple of months, who hasn't eaten in a couple of months, and who really is at a health risk.

In response to Sam's assessment, particularly his use of the referent 'kid', I remind the group that the person in the image is an adult, not a child. All four assert they know this – his face and hair make this evident – yet Sam continues to refer to the man as a boy. Pursuing this, with confusion and consternation they question me as to why the man has been photographed wearing only a diaper. Donna determines it is this, above all else, that mis-places him, that makes him look like a child. The man in the image is dressed in no (other) clothing (besides the diaper) that categorizes him, that serves as a social marker of any kind. Because he is an 'adult' in a diaper, an adult literally stripped to the bare bones except for the diaper, for the group his adult status is somehow contradicted. He is too far outside the norm, their norm - "adults don't wear diapers". As a symbol of infancy and dependence, the diaper marks him as an eternal child. And, as Robin notes: "It's just scary, all of it."



Asking them to consider changing the image with these considerations in mind, Sam offers his opinion. Holding the image aloft, pointing to different parts of it and then sweeping his hand across it in a gesture of erasure, Sam says:

Sam: Well, maybe what would be much better is if we would just turn this picture into, like, a beach, like for example, but not showing him. Instead of having him, like, in the middle of the picture, whenever he's like, physically disabled, and he's like very naked, and he's like very skinny-boned, and he's, uh, wearing a diaper, and stuff like that – instead of having him in the picture there should of just been, like a lot of other people, just maybe having some kind of, um, like, activity and be a fun place, like...

Ann: Including him?

Sam: Well, I mean, um, if it's kind of embarrassing then this wouldn't be including him, I mean, but if he's like un-embarrassed, then 'sure', he can be in the picture if he won't, as long as he won't be embarrassed by that or so.

Struggling with what they regard as a hurtful and misleading representation, the group chooses to physically lift him out of the setting he is in and re-place him, instead, upon a beach – a move that works to accomplish a number of things. In contrast to the original, this image is bright, colourful, welcoming. The beautiful scene has been made the central feature and one's eye is drawn to the convergence of sky, sea, sand: moved to the side of the image, *David* has been re-framed as a secondary element. To a certain extent, the re-staging normalizes his appearance. *David's* nakedness is no longer quite so out of place; his diaper can be re-interpreted or at least confused with a bathing suit. His posture, although unchanged, in this setting more closely resembles that of the typical sunbather. In this space, the stigmata of his disability is less readily apparent; passing becomes more of a possibility and his social position is no longer so assuredly

on the margins. For the group, this is a much more acceptable and less stigmatizing positioning of *David*, and one that they believe *David* would be comfortable with. It satisfies their desire for a new story for David.



Ann: Do we want the same words or different words? When you guys told me about this picture you wanted him on the beach, right? You said him wanted him doing kind of normal things. But you did not like it when he was lying on this mattress all by himself because it did not look natural; it looked like he was a refugee.

Bob: [nodding his head in agreement]

Ann: It could have been that he looked like a refugee, you said, or that he was dead, or he was out in the cold, or in an institution some of you said. You wanted him in a natural place...

Sam: Right.

Ann: ...doing natural things. Do we need words and, if we do need words, what words should be put?

Sam: Yeah, I was thinking instead of putting 'David means Beloved', maybe we could put, like, maybe 'David means Adventurous' or what other ideas do you have? You can just share it.

Bob: That sounds good! I agree with that.

Ann: What do you think, Robin?

Robin: Same thing.

Ann: You like that, too?

Robin: Yeah.

Bob: I like it too.

Ann: Donna?

Bob: How about you, Donna?

Robin: It has to be a good word.

Ann: Do you like that? Adventurous is better than beloved?

Donna: Mm hmm.

Ann: It tells a different story, doesn't it?

Sam: Yeah, I think so, cause there is one that says he is on the bed [covered by the blanket] and that is called 'beloved' and that they are try and warm him and care for him, make sure that he is safe and sound and that he is in a good position and loved and that is why they called it 'beloved', and when he is on the beach with the sand and water and he is enjoying the sunshine and the weather and that, he wants to play with sand, and then it is like a beautiful island outside, and that is why I had to put a word change to say that it means 'adventurous'.

I invite them to consider the text, both the original text and the possibility of a new one. Sam reflects upon the original text but not as attached to the original image – he, instead, reminds us that they all felt that the text, “David means beloved”, was more appropriate to their covering *David* with a blanket in their first transformation of the original (in fact, he makes no mention of the original image here at all). In this, their third re-imagining of the *David* image, the new caption works in the same direction as the transformed image – normalizing *David*. *David* is outside, lying on a beautiful beach, with sun, sand and water. This is a place valued by the group (and by many non-disabled others) – an un-segregated space – and, attributing to *David* the capacity for choice, they believe *David* would similarly want to be somewhere such as this. In this setting, his body is less out-of-place, more easily identified with. Unlike the inhospitable and frightening original, *David*, in this space, invites and welcomes this identification and the group more willingly recognize themselves in him here. But this transformation also extends beyond normalization towards a more subversive disruption of existing meanings of intellectual disability, of bodies like *David's*. As they discuss this change, in particular their use of the adjective 'adventurous', they unsettle the reductive and restrictive inscription of *David* as fragile, as un-able, as a perpetual child, that they read in the original image and open the image to new meanings. *David* does require care, yet he also requires opportunity – for travel, for fun, for 'adventures'. His life need not be misery, it could also be pleasurable. Segregation in an

institution is neither the only, nor the best, option for someone with his care needs – giving lie to the assumption that he cannot survive ‘outside’, beyond the (argued to be) ‘protective’ walls of an institution, the group believes he will do best, will, indeed, thrive with such opportunities. In this regard, *David* is more like than un-like ‘everybody’.

*Chapter 11 – “Oh God, don’t let this be me!” People with
Intellectual Disabilities as Other? Or as Me?*

Introduction



Donna spoke first:

Oh God, I don’t want to be like this, oh God, please don’t let me be like this. I do not want to look like this. I do not want to live like this. I think this is the most depressing picture I ever saw in my life. Do you find it upsetting? Like you’re ready to cry or something? You know!

Donna had the most immediate, intense and full-bodied reaction to this image: staring, eyes riveted to the page, a mix of horror and sadness on her face, she held the image in one hand while forcefully banging the other hand repeatedly on the table in front of her. Fighting against recognition of herself in the image, she is nearly brought to tears. Looking to the rest of the group and to myself, she sought confirmation that we were all as distressed as she by this image, and, I believe, by its implications for her.

I find this fragment a heart-rending telling of much that Donna expresses in her work on the image of *David*. It reveals not only her perception of *David*, but also her sense of (and worry over) self – her sense of Being and of being disabled. She may be talking about *David* here, but she is also, quite clearly, speaking to her own struggle to reconcile her desired self-identification with that imposed upon her (by non-disabled others and, quite possibly, by herself), her vacillation betwixt and between resistance, resignation, and acceptance. Without question,

Donna is the most determined and articulate member of the group as regards giving voice to her feelings about being a person with a disability, and the ambiguity, conflicts, and tensions inherent in this experience. She is also the one to most insistently and persistently return discussions of each image back to her own life.

Blurring the divide between *David* (the real, living person she understands to have been photographed) and the photographic image of *David*, Donna emotionally insists that she does not want to ‘*be*’ like *David*, or (equally distressing) to be perceived by others as being the same as him. She points to the visuality or spectacle of disability; the emphasis on the impairment, the dramatically different (and defective) body that is offered up by the image, and tells us that she does not ever want to ‘*look*’ like *David* either. Speaking to the experiential aspect of disability, she stresses further that she does she want to ‘*live*’ like *David*: on many levels *David* and his life (at least as is revealed to her by and through the image) frighten her. Reminiscent of the concerns the group introduce in the previous chapter, it is extremely important to Donna that we, and others (and even she herself), recognize and accept (and validate) her as different from *David*, as not the same as someone “like that”.

But Donna, like the others, is simultaneously (and constantly made) aware that she shares with *David* the label ‘disabled’: “Do you think if I didn’t have a disability I’d be here right now?” And, at times, she, Bob, Sam and Robin appear at ease with this self-identification (I am reminded of the confidence, self-assuredness, and pride evident when they speak of being self-advocates, of their accomplishments, and of their relationships with each other). But this contentment, this self-valuing attitude is a hesitant one – occupying a precarious position, it sits uneasily with more powerful (individual and collective) understandings of disability as a bad thing, “the worst thing”, as something that no-one, including (especially?) they themselves,

would ever choose to have; understandings strongly embedded in this image and in many others they worked with. The spectacle of the image of *David* unhinges their comfort with identification by others and themselves as ‘people with disabilities’. Stripping from *David* all traces of that which they value – privacy, dignity, independence, individuality, adulthood, capability, value and humanity – the un-doing of *David* accomplished by the image is equally their un-doing. Provoked by their viewing of all the images – but by this one in particular – these tensions are unearthed, brought to the fore, and made explicit in their words and work.

There’s Nothing Wrong with Having a Disability – Is there?



Sam says something interesting as he works with this image:

What happened to the boy and why is, what’s it called, is he sitting out here on a blanket and he’s all naked and why is he wearing a diaper, and what is, honestly, wrong in what happened to him?

This question arises early in Sam’s attempts to make sense of this image, to story *David’s* life to find some meaning for what he is viewing. I think Sam meant to ask “what’s wrong *with* him?” but his phrasing of his question functions to challenge the notion that there is, indeed, something wrong with *David* – “what is, honestly, wrong in what happened to him?” Donna’s ambivalence is similarly visible when she remarks: I don’t think there’s [anything?] wrong with anybody who has a disability, I don’t find, you’re born like that, that’s the way life is. God made you like that. You can’t do anything about it.

As was considered in *Bob's Blanket*, a double meaning appears to rest in her words – the tone suggests a hint of pride, the words imply at least acceptance (there is nothing wrong with a person with a disability), but the fatalism, the resignation, serves to temper this. People with disabilities are “born like that”, made “like that” by God, and “you can’t do anything about it.” I ask them where they think the *David* picture comes from. Sam wonders if the image is “a [service organization] charity picture” – an interpretation echoed by Bob, Donna and Robin. This appears rooted in their perception of the man in the image as being vulnerable, in need of support (an understanding elaborated upon more fully in the chapter, *Bob's Blanket*). What comes to light as they continue this discussion is the disconnect between self-identification as a service-user (which they freely acknowledge) and recognition of the link between themselves and the children and adults with intellectual disabilities - as representatives of *all* service-users with intellectual disabilities – in the charity images created by service agencies. As they repeat here, all four of the group members are actively supported by social service organizations. Between them, they receive direct social work support; housing and activities of daily living supports; and staff support to participate in social, recreational, and political/social change activities. They all seem to take for granted that these service organizations use photographic imagery for fundraising purposes but I am not able to determine just how much they think about the fact that this charitable activity directly benefits them. Also, they are adamant – they would never consent to their own images being used to raise money, but, at the same time, they speak excitedly, if not fondly, about seeing their friends’ images on billboards, posters, advertising and fund-raising materials. I get the sense that public photographic images of their friends, used as they are by the service organization, are (at least somewhat) acceptable in that these images (unlike the *David* image) are understood by Donna, Sam, Robin and Bob to look a bit more like “us” than like “them” – the (almost?) unrecognizable other represented by *David*, *Tracy*, and the

child in the *Blatt* image. This sense is strengthened when, today (and many, many other times throughout the course of the project) they encourage me to introduce my daughter, Frances, to “the people who take the pictures” at a particular service organization with the aim of having Frances become, in effect, the poster child for the agency. Citing that the young girl who has been the featured poster child for the past few years is now “grown up”, they believe the agency needs a “new one” and that Frances would be an ideal candidate as she is “very cute”. They seem to think that Frances, and I, would find this desirable. To my ears, theirs is a very complex and contradictory relationship to public images, identification with people with disabilities in these images, and self-identification as a person with an intellectual disability and, as their own position shifts, “between the seer and seen” (Garland-Thomson, 1997:136).

“He’s More Disabled than Me!”

As they react and respond to the *David* image over the course of many meetings, their tone frequently flips between one approaching positive acceptance, one of sad resignation, or one that strongly pushes against (self)identification as disabled. For example, at one point in his work with the image, Robin asserts in a casual, almost off-hand way, “That’s how he was born, like that.” There is no derision, no despair; neither *David* nor his impairment is diminished – this is just how *David* is. Other discussions in this vein unveil an empathetic identification with *David* – like they themselves, *David* has an intellectual disability. But, this same language is used by Robin later in a much different way, connected to feelings of sorrow about *David*’s disability (and, less explicitly, about his own) : Robin tells me that he feels sad that *David* was “born *like that*...It’s just hard to be born *like that*.” Here is an exchange between Robin and Bob that follows soon after.

Robin: That's how he was born, *like that*.

Bob: Some people are *like that*.

Robin: That's how *they* are.

The emphasis and inflection appending the words “*like that*” and “*they*” subtly shift their meaning from one of easy acceptance, to one that works to other *David*, to denote his (devalued) difference. Their words have become a slur, a regrettably common slur (and one that in other meetings they concede has been habitually used against them) that pathologizes *David* and essentializes his disability. *David's* disability is elemental to his being – it is not constructed (by the image), it is not the product of what has been done to him or the barriers that exist for people with impairments: *David* was born “*like that*”, that’s just how he is, *but*, their words also make plain that this is not a good way to be. And, while they may care about this man, the intent is to use this language to distance or distinguish themselves from *David*, both *David* as a real person and the representation of intellectual disability imaged in photograph of *David*, to establish that they are un-like him/it. The overlap here with the previous chapter is obvious: not only do they regard *David* (and themselves) as other in the eyes of non-disabled people; they are also strongly compelled to other *David* (and themselves?) from themselves.

Very carefully, I broach this topic: Do they understand their own intellectual disabilities to be the same or different from that of ‘David’?

The first response is an unspoken one - their discomfiture signaled by their silence, the averting of their eyes from mine, some squirming in seats. Moving in this direction is not where they wish to go. The silence goes unbroken by me but, eventually, they tentatively respond. Each successive speaker gathering strength from the one before, the group members do (albeit reluctantly) admit to each having an intellectual disability, and to sharing this commonality with each other *and* (giving voice here to the unsayable) with *David* (*and* with *Tracy*, and with the

child in *Blatt*). Yet, today, they will travel only so far in acknowledging this particular ‘truth’: all are emphatic in the assertion that their disability is, somehow, “different”. Robin summarily announces:

I’m not the same as the people in the picture, they are different than me, more disabled than me. If their picture is in the paper they have a worse disability than me.



Connecting, as it does, the ‘real’ people captured visually in the photographic images, Robin’s phrase, “the people in the picture”, reveals again the recurrent blurring of the two so evident throughout their work. I push them to elaborate, to try to tell me just how their disability differs. In a rather long and convoluted exchange with Robin, I learn that he believes *David* “has mentally challenges, it has to be worked on”. *David’s* disability is so severe that it needs to be “worked on a lot”, whereas his, Robin’s, disability is much less complex and, consequently, you “don’t need to work on it as much.”

Sam’s focus is almost exclusively on *David’s* physicality as explanation for the difference between them. A large, strong and healthy young man (quite close in age to *David’s* age at the time the image was produced) Sam sees little of himself in *David’s* body. Unlike Sam, because

of his “crippled” and “crooked” body, *David* cannot move, cannot function, he is weak and physically unable.

Picking up this thread, Bob matter-of-factly maintains *David* is different because "he can't move as much, and he just doesn't want to - he might want to but he can't function" as well as he (Bob) or the other the members of the research group can - "(h)e can't function like a normal person."

Their focus, in this exchange, seems limited to the question of being, particularly of ‘doing’ for oneself which *David*, in this image, is visually portrayed as being undeniably unable to do in any significant way. The violence of this image is in how this non-doing has immediate and profound impacts on the meaning of *David* himself. The extremeness of the image would appear to make differentiating oneself from *David* relatively easy for *David*, as noted, has been staged as being so unlike the majority of people – with and without disabilities – as to be incommensurable, too far beyond the limits of conceptualization of “same”. Nonetheless, I am caught off-guard by Bob’s un-self-conscious use of the term, “*normal*”. In light of his previous concern for the man in the image, his lack of critique is somewhat surprising. Characterizing *David* in this way, he neatly separates *David* from the ‘normal’ majority (by inference, a group to which he belongs), taxonomically branding him as not-normal, abnormal, un-like Bob. Seeming, at first, to ignore his self-identification as a person with an intellectual disability, for me, Bob’s choice of words effectively dehumanizes *David*, othering him to the extreme. Exemplifying *David*’s diminishment in their eyes, pity tinges the words of Sam, Robin, and Bob. Donna makes this explicit:

No, this is [pause as she thought about what to say] sad. I feel sorry for this person because he has this problem....I feel sorry for people like that, you know.

Bob, Sam, Donna, and Robin push *David* (the person) from their own circle of people with

intellectual disabilities and a hierarchical ‘us/him’ dichotomy is forged in their (to them, necessary) assertion that their disabilities are different, less devalued. In these ways, the group reveals their knowledge/belief that intellectual disability, exemplified in such surfeit by the image of *David*, is so absolutely undesirable that they must therefore distance themselves from it; from the label “intellectually disabled’, from the image, from the disabled person in the image, and from others with disabilities similar to those of this person. (I am reminded of Sam’s words, that intellectual disability as represented by the *David* image is "the most scaring and horrifying and frightening and terrifying thing that could ever happen.") This dissociation from *David* seems, in this way, a means of privileging themselves, of lessening (if not completely erasing) the gap between themselves and ‘normal’.

At this point in our conversation, all four stubbornly, even violently, resist identification or association with the image of *David*, a hesitation reflecting their fear of being viewed as being the ‘same’. If this man is understood by non-disabled viewers as the prototype or public face of ‘intellectual disability’, they will renounce their self-identification as intellectually disabled – they do not want to be regarded as ‘that kind’ of a disabled person. At the same time, they actively work to denounce use of this image of this man as the face, the representative, of people with intellectual disabilities – a ‘truth’ they find more than a little problematic. The group unanimously asserts that they do not know *anyone* who looks “*like that*”, (like *David*) in any of their neighbourhoods, communities, or programs. While internally I question the veracity of this claim, I am prepared to give them the benefit of the doubt for there is the chance they are taking my question literally, in which case it is highly unlikely they would encounter a man who looks like the man in the *David* image (clothed only in a diaper, lying on a mattress) in the community – the image is just too un-real. As our discussion continues, however, a trickle of doubt emerges.

Robin relays that he has, *maybe*, seen someone like this but, he is quick to point out, he doesn't know him. Soon after, he admits that he might also know of another man "who's a bit like this, a little bit disabled". But he seems to regret this confession and is, again, careful to minimize this knowing. Sam briefly mentions a woman he met/saw at a conference once (but quickly puts even more space between the woman and himself by lauding her as a larger-than-life – and thus somewhat less-than-real - “inspiration”). Donna talks of a woman she has seen in church who has seizures that cannot be controlled – clearly frightened by the woman’s seizures, her thin and wasting body, and her obvious physical decline, Donna, too, is quick to distinguish herself as different, as unlike this woman.

Bob’s positioning of the man in the *David* image, himself, and people with intellectual disabilities like his own (I understand him to embrace here the other members of the group) within the context of a ‘normal/abnormal’ dichotomy, emerges again in his work with the *Tracy* image.

Bob: Like we’re different people than what they are because we’re in the apartment program, but we still have counsellors, right, looking after us, but they have to have different, special needs, ‘cause they’re special kids, what they call special needs, that’s right, to help them out....

In this fragment, Bob identifies some similarity – “but we still have counsellors, right, looking after us” – but is more concerned to demarcate the dissimilarity between ‘us’ and ‘them’, between people with disabilities like he and the group members share and those of “special” people like this young girl in the image. In the fragment below, he is more judgmental:

Ann: What do you feel when you look at this picture?

Bob: I feel sad, inside, because the person just can’t function like you can, like normal, can’t function as normally as you can, she has to be in a wheelchair and cared for all the time. Some people, some disabilities are like that. But some disability people they go by WheelTrans. This girl might probably have to go by

transportation. And that's [pointing to the woman holding the young girl] probably her sister.

Confounding this somewhat, Bob later shares with us that his father has recently had a stroke resulting in physical impairments that necessitate his use of a wheelchair and placement in a long-term care facility. Bob does not ever refer to his father's situation as "sad", or to his father as not "normal".

Staying with questions of normality attached to the singularity of functional ability, Bob spends time with the image, pointing to it, to the appropriate body parts, as he itemizes the things the girl cannot do for herself (e.g., points to the girl's and then his own mouth when talking about how the girl can't eat).

Bob: Oh, she's sad because she can't go to the washroom herself, needs help, cause of her disability...oh, and she can't talk, her speech is like, not like other people...

Ann: She can't speak either?

Bob: Right.

Ann: And that's a sad thing, when you can't speak?

Bob: Right, that's right. It's a sad thing.

Bob: And she's not smiling very much in this picture.

Ann: And that strikes you? What do you think that means?

Bob: That means she's sad, that's right, that's another thing [that strikes him].

I ask if there is anything else that makes the girl sad:

Bob: Um, 'cause the person can't function any more, like we can, they don't uh, they have a brain but their brain doesn't work properly, it's a little different, and they're slow learners, and uh, they're sad, too, 'cause they gotta go to workshops, they can't function like I can, they can't get a normal job, 'cause they gotta go to workshops, people that are in wheelchairs.

Bob also noted that the woman holding the girl on her lap is smiling and explains it this way:

Bob: Because she's [the woman] happy, that she's helping her out.

Ann: Happy to be helping her?

Bob: Right, helping her sister.

Two thoughts strike me during this piece of conversation. Recalling several conversations with Bob, I know that he holds 'workshops', those segregated day programs that ostensibly provide vocational opportunities to people with intellectual disabilities, in low regard. He, himself, has a paid job in the community and this is vitally important to his self-esteem: I am quite confident that he would be extremely despondent should he have no choices but a workshop. But I also remember Bob's sharing of his sadness over not being able to have pets as his worker has determined (after any number of attempts on Bob's part) that he is incapable of caring for them, that he can't 'function' in this regard.

Returning him again to his observation that the girl in the image was not smiling, I asked him if people who use wheelchairs, who have disabilities like this girl has, feel sorry for themselves and think it is sad to have a disability.

Bob: They probably do.

In another meeting, Robin tells me the image makes it look like the girl has committed suicide – he points to her closed eyes and sprawled body that, in its complete lack of apparent self-control, appears lifeless, and to her head which looks, to him, as if it has banged (been banged) into the lamp table behind her. Later, he wonders why the woman holding her is smiling – an alarming pairing to my eye, suggesting as it does that the woman might be happy the child is dead – but I cannot ascertain if his two thoughts are coupled. Remembering once again that this girl was chosen to represent Tracy Latimer, the disabled child killed by her father, Robin's words assume a more frightening significance.



There are tensions and ambiguities inherent in their descriptions and interpretations of the ‘truths’ read in the *David* and *Tracy* images and the ‘truths’ they understand to exist in the lives of the “people in the pictures” (and those of their own lives); most notably, when Robin, Bob, Sam, and Donna are asserting that having an intellectual disability is “okay”. Yet, they often seem quite unaware of these contradictions. Listening to them, I understand them to share the dominant cultural assessments of intellectual disability as tragedy, undesirable, and frightening and the valuation of narrow constructions of normalcy and ability that they read in the images. Weaving their own life stories into these interpretations, their experiences too frequently support these assumptions and Donna, Robin, Sam and Bob all yearn to be recognized as being “normal”.

While this longing co-exists with an acknowledged need for support, the need for a positive sense of self and even a feeling of pride in themselves, there remains the imperative to unequivocally distinguish and distance themselves from the people with intellectual disabilities that they see in the images; people they are convinced similarly recognize the tragic nature of their own situations. Overlapping their revelations in the previous chapter, they are anxious to make their own disabilities in-visible, not-visible to people without disabilities. At the same time, they themselves resist seeing the un-seeable in the images, that which they know to be there; their own similarities to the people captured by the photographer’s lens: this frightens them. Oft times powerfully disavowing any similarity whatsoever between themselves and those

in the images, their dis-ease (Campbell, 1999) is strong.

The Disabled as Me? Yes, as Me



- Donna: I want to work on the clothing one.
 Robin: Same thing.
 Ann: You too, Robin?
 Sam: Yeah, me too.
 Ann: Bob?
 Bob: Mmm hmm
 Donna: I, I, uh...
 Bob: The one with the hat.
 Ann: The hat?
 Donna: Yeah, I like the one with the hat.
 Sam: Me too.
 Robin: Mmm hmm.

Presented with a number of images, the group chooses these two to work on at this meeting, and to begin with the photograph of the child wearing the hat. Having worked already with another pair of images from the *Benetton Sunflowers* campaign (the boy held by a woman, and the girl seated on the bench with a man), Donna, Sam, Robin and Bob were aware of the origins of the images but we talked briefly about them again here. They are noticeably impressed that *Benetton* is an “expensive” store, a “nice” store. As Sam looks on affectionately, Robin enthusiastically tells us he “likes fashion” and enjoys shopping at more expensive stores and buying “decent clothes” – “hey, that’s just me.”

The smiling face of the child (who clearly has Down syndrome) is facing the camera, although his eyes are looking downwards. Asking what they see when they look at the image of the child in the hat, the child's "happy smile" is immediately mentioned; a smile that tells Robin something significant – "he feels good about himself." Sam pipes in to add that "it seems like he's having fun, he's enjoying himself." Somewhat restless, fidgeting in his seat, Sam then raises his hand to add the following:

Sam: I'm so glad this picture's easy to talk about. The other one was very hard to talk about, like remember the ones from the past, like we were, like, seeing before the presentation?

Bob: Right.

Ann: Right, so why is this one easier to talk about?

Sam: Right, well, 'cause it obviously shows a point about what this was about, and what honestly this one's about and what's going on, like, you can get what you can say. But the other ones, like in the piece of paper [newspaper], doesn't make a point about it, and it doesn't make a point about something and also you can't get to what to talk about, too.

Ann: OK, so let me just make sure I understand – the other ones were hard to understand you said because they didn't make a point?

Sam: No.

Ann: So you had to try to figure out what it was?

Sam: Yeah, that's what I mean.



As a portrait, the young boy's head and upper torso consume almost all of the space of the image. There is nothing else contained within – the bright, textured background may be a wall

but this is not certain, a name across the front of the hat is impossible to read. In the absence of any contextual information (beyond knowing this is an advertisement for a retail clothing chain), I am curious as to why Sam believes this image to be so easy “to get to what to talk about”. I pursue this with Sam, wondering what it is that makes this one so much easier to understand, to story:

Ann: So what do you think this one’s about, why is this one easier?

Sam: Um, what I would say that this one is about, um, is that, honestly, there’s a boy who’s um, in the picture, um, and looks like to me what’s around him is there’s a pile of, ground of snow, and, uh, maybe he’s like, uh, doing some kind of, uh, making like a snow angel or, like, just playing in the snow and having some kind of fun and, uh, just playing around, like just playing with the snow for fun, like, um, just for (pause)...

Ann: OK.

Sam: ...just for, what’s it called, enjoyment!

Ann: OK, OK, so he just seems to be having fun?

Sam: Yeah!

Ann: OK, and you think maybe just playing in the snow, making snow angels...

Sam: Making snow angels by, like, laying down on the ground and...

Ann: ...OK, OK, alright. What about the rest, what about you Donna, when you look at this one what do you think?

Donna: To me in the background it looks like there’s water, the ocean, like the blue sky, that’s why it looks like to me. But she looks happy, she looks happy wearing those clothes. She looks very nice in those clothes. (As Donna speaks, Sam is vigorously nodding his head in agreement.) I like the hat on her, it’s very nice. She’s very happy there. I would be too if I was wearing your clothes (holding her own head in her hands while playfully directing this last comment not to me but to the child in the image).

Ann: (Laugh) OK. What about you, Bob, what do you think?

Bob: I think the little boy looks very happy. He’s sort of liking with his hat on, he looks nice with his hat on, and no-one’s making fun of him so that’s good.

Ann: And what makes you think no-one’s making fun of him?

Bob: Uh, ‘cause the way he’s dressing, he’s dressed up nice and he’s got a nice hat on and everything.

For Sam, the image is, in Berger’s language, a short quotation (1982): its meaning is simple; it is about a child having fun. With a shared emphasis on the child’s engagement in typical childhood behaviour, there is some divergence as to the group members’ understandings of just what activities the child is engaged in: the indecipherability of the background would seem to

open itself up to multiple interpretations. Nonetheless, Sam, Donna and Bob are convinced the child is happy, is enjoying himself (or, in Donna's case, 'herself' for Donna waffles in her assessment as to whether the child is a girl or a boy). Bob returns the discussion back to the connection between one's appearance and being teased and what follows is a conversation reminiscent of their dialogue around the importance of clothing when working with the *Rosie* image. This is a discussion Robin is eager to participate in – clothes are high on his list of interests – and he leads the conversation for the next while.

Robin: Are you thinking about this picture (*Benetton*)? I think it's interesting.

Ann: What about it is interesting? What part do you find interesting?

Robin: About the store...

Ann: About the store?

Robin: ...about the store, I forgot the name of the store...

Ann: *Benetton*

Robin: ...*Benetton*. I never heard of it before...

Ann: OK.

Robin: ...That's why. (laugh)

Ann: OK. Are you surprised, are you guys surprised that a fancy store would use pictures of people with disabilities to sell their clothes?

Donna: Yep, yep.

Sam: A fancy?

Ann: A fancy store like *Benetton*.

Sam: Oh, a fancy store!

Ann: Does that surprise you? That an expensive kind of store would use pictures of people with disabilities to sell their clothes?

Sam: Well, basically, yeah, it would make us feel surprised. Like, it's in a fancy store, what kind of, like, items that they kind of sell for the kids or anything. Yeah.

Ann: OK. Do you, have you ever seen other stores use pictures of, um, people with disabilities?

Donna: No, this is the first time.

Sam: No, not that I know of. This is the first time, first time.

Ann: Do you ever see pictures of people with disabilities in the catalogue or stuff?

Robin: No.

Sam: Um, no.

Robin: No way, only normal people and stuff.

Ann: OK.

Sam: But maybe in newspapers I would, like...

Robin: Not really. Like you see, like, a person that is in a murder trial, like killing, things like that, that sort of people – you know the way they look, their face, kinda, they’re kind of up to something, you know?

Ann: Right.

Robin: That’s what, that’s what in the papers – no way like that (pointing to *Benetton* image).

For a few minutes, they are caught up in this discussion about the rarity of the presence of images of people with disabilities in retail marketing materials (e.g., advertisements, catalogues) which, to their minds, exclusively solicit/include only images of “normal people and stuff”.

While Sam notes that he has seen images of people with disabilities in the newspaper (I assume he is referencing those we have already worked with), Robin quickly checks this: only images of people doing “bad” things are included in the newspaper – never images like this *Benetton* one, “good” images of people with intellectual disabilities.

With the exception of Robin, they all seem rather disengaged today. Listless, they answer the questions but, for the most part, display little enthusiasm. Donna sits with her head resting on her hand; Bob looks a bit ruffled – hair in all directions, clothing a bit wrinkled, his body folding in upon itself as he sits beside Donna. I catch Sam frequently gazing out the window – a gaze interrupted by the occasional yawn or stretch. They decline my offer to make the meeting a short one and apologetically assert their desire to carry on. Moving them along, I ask them to consider the story the image tells and, once again, they tell me it is simply about a happy child having fun outside.

Today, unlike any other day, I am having to work very hard to keep everyone involved and engaged with the image. There is little spontaneous contribution from anyone other than Robin, who seems especially motivated to talk about clothes. This is unusual. I am not sure if they are all simply tired or if the image does not really challenge them – their body language could be used to argue either conjecture.

Ann: And why do you think the little boy’s smiling?

Donna: She’s happy!

Ann: Any idea why you think the little boy's happy?

Donna: He's smiling because he's happy that the photographer took his picture.

Ann: Alright.

I am struck here by Donna's determination that, in this instance, the child is pleased to have had his picture taken by the photographer. The group members have really only suggested this twice before – when working with the *Benetton* image of the woman holding the boy, and with the de-captioned *United Way* image (however, upon reading the caption and accompanying text, they quickly reversed their assessment for this latter image). For the majority of the images they have selected to work with, they have held firmly to the notion that the people with disabilities in the images would have actively (and angrily) opposed being photographed and I remind them of this now. Sam interjects to suggest that, in his estimation, the image is a good one because the child is photographed in such a way as to promote for people with disabilities “life with dignity and diversity and respect” – it is like an advertisement for the importance of support for people with disabilities, to give the message “to be included like, for kids belong together, for that matter”. That this reflects ideals they themselves hold dear, attitudes and opportunities that would much improve their own lives, goes unstated. Sam notes, too, that he feels the child has been photographed “in a good condition” which precipitates Robin's conjecture that “he has good [self] esteem”. At this I am reminded of Robin's earlier assertion that the child in this *Benetton* image “feels good about himself.” This connection is made stronger when we explore the feelings elicited by the image:

Ann: Alright, very interesting, alright, OK, um, when, you say when you look at this picture you see a little boy who's dressed very nice and seems really happy. So how do you feel when you look at this picture?

Donna: Makes me feel good, it makes me feel happy!

Sam: Same here!

Donna: Yeah, it makes me feel good, I feel good about the picture.

Bob: Really good.

Donna: I feel happy.

Ann: Sorry, you feel good about what, Donna?

Donna: I feel good about the picture. I'm happy to see this picture. It makes me feel good. It makes my day, you know!

Sam: Me too, oh my God! Same here.

Bob: Yeah, yeah, makes you feel good.

Ann: Just what do you think about when you look at it? Does it remind you of anybody or anything? Is there anything in your life that it makes you think about?

Bob: No.

Ann: No? OK. What about you Donna? What does the picture make you think about?

Donna: (long pause) Uh, it makes me think about me?

Ann: OK, what do you think about you when you look at it?

Donna: It makes me think about that I have a disability.

Ann: How does it do that?

Donna: Um, what do you mean?

Ann: Well, why does it make you think about the fact that you have a disability?

Donna: Because I was born that way.

Ann: OK (uncertain), so are you thinking, maybe because this little boy was born with a disability, is that what makes you think about that you were born with a disability?

Donna: Yeah, yeah.

Donna very much likes this image; "I feel good about the picture. I'm happy to see this picture. It makes me feel good. It makes my day, you know!" Speaking to the image as a product, she has no argument with the creation of this particular image of this particular child with an intellectual disability. When pressed, she proffers that the image makes her think about herself, about being with a person with a disability. She does not venture here into the familiar territory of oppressive and hurtful experiences. She remains quiet, thoughtfully looking at the image, and will say nothing more about this. I am brought back to her earlier engagement with the image, the point at which she playfully addressed the image directly, wistfully, 'telling' the child in the

image how happy she herself would be, how good she would feel, if she was dressed like the child. I wonder, but do not ask (why not?), if, in some way, she is not a bit envious of what she understands this child's life to be? She perceives the child to be well-dressed (does this signify he is valued?), to be happy. In their storying of the child's life, Donna and the others believe him to be playing, to be engaged (as many 'normal' children are) in numerous adventures (at the ocean, watching the whales, making snow angels). Like Sam, Robin and Bob, Donna feels much contentment contemplating *this* life for *this* disabled child and she takes great pleasure in looking at the image from this perspective. Based upon what I have learned from Donna about her own life over the course of our work on the project, I wonder if she is considering how her own life might have been different, that perhaps she might have been a happy child (and, now, a happier adult). Whether she might have brought joy to people's faces (as this child does to hers), rather than reactions of anger, fear and rejection? While not articulating such today, spurred on by conversations she initiates about my daughters she does voice these ideas in conversations outside of the project; wondering why she was not loved, valued and respected by her family as she perceives this child and my own children are.

I asked them if the image said 'good things' or 'bad things' about people with disabilities.

Donna: Oh, I like this one, I like it. It makes me happy. I like what this one's about. This is the best one – I like it (laughs).

Bob: Me too.

Sam says that this one is "appropriate". Pursuing this, what he means by "appropriate", he and Robin engage in a comparison of this image to that of *David*, an image they have many times deemed not appropriate and shocking. Not unsurprisingly, they list their many objections to the *David* image and cite the differences between it and this image. Donna effectively sums this all up:

He's [the child wearing the hat] got clothes on, he's got clothes on and he's not lying and he's not naked and skinny like the guy in diaper. He's not depressing, this guy makes me happy.

Interestingly, Sam adds to this that the child is having fun and “just getting what he deserves”.

What I come to understand from Sam is that the child deserves to have fun but Bob twists this a bit and suggests it is more about this being a “good picture” – the idea that the child deserves to be imaged in a “good” way. Extending this, I wonder if they feel non-disabled viewers would regard the image as they do and I ask then what non-disabled viewers might think about people with disabilities upon viewing this image:

Sam: Well, the point is, he's honestly, uh, in a more proper standard and he's also, like, well dressed and he's very clean and he's healthy and, uh, about his appearances making a point there about what's appropriate.

Ann: OK.

Sam: And it's also telling you exactly what's, um, the good thing about the person with a disability and it also makes people think of a positive attitude, have a positive attitude I mean.

Bob and Sam make the case for the necessity and value of care-ful imaging, for attention to responsible photographic representation. Having been photographed “in a more proper standard”, in a manner that does not shock, demean, or dehumanize people with intellectual disabilities but, instead, affords dignity and demonstrates respect, this image is a “good picture”, one which tells a “good thing” about persons with disabilities and which will lead (all) viewers towards more positive attitudes. In response to Sam's last comment, Bob asserts that it wouldn't matter to the non-disabled viewer that the child had a disability – only that the child was smiling. Donna concurs, suggesting these viewers would care about the child. For a short while they sit, comfortably, with these thoughts. However, they do not entirely trust non-disabled viewers to see it as they do. Flipping the notion of just whose mind is ‘impaired’, Sam goes on to say:

Well, one way or the other about people that doesn't have a disability or something, people who are just not polite and just doesn't understand, yeah, they would just make fun and they would be so rude and despicable and just very evil and harsh and something, but, but on the other hand, innocent people they would, obviously, um, understand and realize the point and, uh, think this is honestly, what's it called, a, a caring thing. People who just doesn't understand just has a challenging mind.



Sam: "Cute picture."

At this point in the meeting, Donna, Sam, Robin and Bob choose to work on this second *Benetton* image – an image of a little girl with Down syndrome in colourful clothing framed, again, against a bright, albeit neutral, background. They briefly comment on the sweater, and on the word "Love" on the child's turtleneck. They note her gaze towards the camera, her smiling face. Again, they indicate their sense that this child is also a happy child. They spend very little time on this image – really only repeating their thoughts about the *Benetton* image of the boy in the hat. They do, however, get quite caught up in the messiness of the child's hair and are uncertain how to interpret this.

Ann: Do you see, Bob or Donna, do you see anything bad, that you don't like about this picture?

Bob: No, it's OK.

Donna: No, other than I can see her hair sticking up!

Ann: I think that's supposed to be stylish, but I don't know...(laugh)

Donna: Oh, oh.

Pointing to the child's hair in the image, Donna singles this out as the only feature of the image that troubles her. My suggestion that this might be a deliberate attempt at style elicits laughter and Bob ruffles his own hair to copy/mock the styling of the child's hair. Much joking ensues and then I draw them back to the work by asking them to talk about the story they feel the image tells.

Sam: ...how people, what's it called, um, faces, um, how the way they, like um, are normal or how they relax...

Bob: Right.

Sam: ... how they are relaxed with their, um, insider's, um, appearance – it's just depending on appearances, that's it.

Ann: OK, so what do you think is the appearance of this one? Do you think this (pointing to image of girl with sweater) tells a good story about disabilities like this one (image of child with hat) tells a good story?

Bob: Mmm Hmm.

Sam: Yeah, that one's OK, I mean, that's not anything bad!

I am intrigued, albeit uncertain, about Sam's use of the term "appearances". His explanation is difficult to follow but, at its heart, I understand him to mean two things. First, that the child is/presented as being content, satisfied with who she is as a person with a disability: "relaxed with their, um, insider's...appearance". "Insider's appearance" seems commensurate with Robin's use of the more common term, "self esteem", as attributed by him to the child with the hat. With this image, of the child with the sweater, Sam goes further: in being so at ease with who she is, the child is (even with a disability) "normal". But "appearances" also references the way the child has been visually realized: he points to how she is dressed, and to her being photographed in an "appropriate" way. As he noted with the image of the child with a hat – she is "clean", in "good condition", "healthy". For Sam, so much is "depending on appearances"

and, in the case of these two *Benetton* images, there is “not anything bad” with the “appearances” of these two visual representations of people with intellectual disabilities.

Looking to wrap up the meeting, I ask them “Would you want to change these pictures?”

Immediately, both Donna and Sam raise their right hands in a gesture to stop me, while all four of them sit forward in the seats and, with clear strong voices, tell me “No”. Not one of them wants a single change made to either image – “no way”, “never, ever, ever change it” – citing each to be “perfect the way it is”. They are quite insistent here, demonstrating much more energy and emotion than at any other time today. I ask them, then, if they would like to add words. Starting now to joke with each other and with me, they bandy about a number of different ideas as to which words they might include and how: dissatisfied, they decide to pick this up next time. Before leaving, however, we start talking about how they might like, in the project, to use their personal photographs, the ones they brought to the group early on. Sam and Donna each have several in their project files, Bob has one. Robin’s preference is to keep his personal photographs private. We have spoken, off and on, about how to incorporate these (for they are keen to do so) without yet landing on anything that sufficiently inspires them. Smiling, Sam and Donna and Bob excitedly pull their own photographs out of their files and begin talking about their favourites; sharing the memories behind the photographs and conveying what each image means to them. I am struck by their happiness, the ease and absence of strife in their words and bodies at this moment. These cherished images represent people, places, and activities which bring them joy; they reflect the positive, the treasured, aspects of their lives. As they continue, Donna raises for consideration the possibility of pairing their own images with these two *Benetton* images: in light of their feelings about their personal photographs, this is a pairing that makes sense. Regrettably, many of their personal pictures include other people –

friends, family, co-workers - necessitating a discussion around Donna's, Bob's and Sam's obligation not use these images without obtaining consent. Practicality thus enters the picture and the decision is made to, instead, direct Ted in the creation of individual portraits to pair with the two *Benetton* images.



Mimicking the staging of the *Benetton* images, the portraits of Bob, Donna and Sam are in colour, well lit. The background (a park) is obscure enough to not direct the reading of the images in any significant way. Bodies directed toward the camera, they smile and their eyes return the camera's gaze. Most resembling, once again, a personal photo album, this collection of images is meant to signify persons with disabilities who are happy, who feel good about themselves and who want the viewer to know this. Captions are thus unnecessary. At this instance, Donna, Bob and Sam are as comfortable in their own skins as they assume these

children to be in theirs. There is no need to push against these images (for these are “good pictures”), to resist identifying with these children (in fact, Donna, Bob and Sam are anxious to be seen, in this instance, as the “same”) for anyone viewing these – *their* – pictures (not just photographs *of* them, but images whose production they have controlled, images they are pleased with) would/should be led to care about them, respect them, and treat them well.

Donna: If you put, if you put maybe my picture beside her (child in sweater), that would be nice! And we can be as friends, you know what I mean?

Sam: MmmHmm



Ann: Bob do you want to maybe sit here, where I can see you? This is the one you wanted to look at. Tell me, why did you like this picture?

Bob: Because I like the guy who smiles, they are so cute. I like the little costumes, the stars on the wands and their shoes...I like this, too, the trees and grass and leaves coming out – it looks nice.

Ann: When you looked at it first you saw the smiles, outfits and stars. How does the picture make you feel?

Bob: It makes me feel good to see somebody smiling instead of being sad.

Ann: When you look at it, what kinds of things do you think about?

Bob: I think about when you are happy.

Ann: Anything else you think about when you look at it?

Bob: I like the masks.

Ann: Why do you like the masks?

Bob: Because it's like a costume party.

Ann: Do you like costume parties?

Bob: Oh yeah!

Ann: Why do you like costume parties?

Bob: They are fun.

Ann: What is fun about them?
 Bob: I get to dress up.
 Ann: Can you tell me why you like to dress up?
 Bob: Just for the fun of it.
 Ann: Does it let you be something different?
 Bob: Oh yeah.
 Ann: So you think they are going to a costume party and you think it might be fun to go to a costume party?
 Bob: Yup.
 Ann: Any other reason they might be smiling?
 Bob: Because they are happy.
 Ann: Are they happy about the costume party? Or is there some other reason they are happy?
 Bob: Just because of the costume party.

At another meeting, Bob selected this image to work with immediately. He was obviously quite smitten by it: looking at the image with what I regard to be fondness, he holds it gently and smiles throughout our exchange. His eyes slowly roam across the entire surface of the image as his attention is caught first by the smiles on the faces of the women, then by their costumes, and finally by the surroundings – “the trees and grass and leaves coming out – it looks nice”. Despite the overall darkness of this black and white image, Bob has little trouble discerning the details. The marked contrast between the women dressed almost entirely in white (a contrast so strong the stars on the shoes and wands appear almost luminous) foreground against the much darker background of trees and grass may have influenced his viewing but goes unremarked upon by Bob or I. He takes pleasure in certain details and in the image as a whole – its overall effect is, for Bob, one of inducing a feeling of joy. What persists for Bob is the happiness he reads on the faces of the women in the image – for him, this is a striking change from many of the other images we have worked with (e.g., *David*, *Tracy*, *Blatt*) – and is the feature he has consistently been drawn to in other images he has liked (e.g., *United Way*, *Benetton*). The happiness of others, as has been demonstrated in his work throughout the project, is especially important to Bob, and he informs me that he feels “good to see somebody smiling instead of being sad.” The

image evokes personal memories of times when he, himself, was happy – being at costume parties, dressing up. Bob will not be deterred: despite my attempts to push him towards a broader interpretation, he lingers in this emotional register and keeps it simple. To each of my many questions he (patiently and politely) responds the same way: the image is about happiness, it is about having fun.

As we continue to talk, however, Bob does step beyond this singular explanation. Elaborating, he also (shyly) enlightens me as to the gaze he bestows upon the image. Bob shares with me that the “girl” on the far right edge of the image reminds him very much of his (now deceased) girlfriend, L., “when she was smiling.” “L. smiled a lot. She was a very happy girl.” Pointing to this young woman’s dress (the one just visible under the paper costume) he says that L. dressed the same way and that she, too, had Down syndrome. Strengthening this recognition, he goes on to tell me that “that girl reminds me of L., the way she holds the star.” Understanding the image to be documenting a costume party, it now begins to also (wishfully) document an aspect of L.’s life as Bob is convinced L. would have very much desired to be at this party:

L. would have liked to dress up for a costume party like this. She would have had fun at this party. She liked parties. She liked costume parties, liked Michael Jackson. Yeah, yeah. She also liked the Maple Leafs.

His response to the image is unmistakably linked to L., to his love for her and the loss he continues to feel, even these many years after her death. It is this that initially attracts him to the photograph and which further makes the women in the image very real to him.

The story Bob tells himself when he looks at the picture is that the women are having a party where they are pretending, “doing a play about kings and queens” – as is indicated by the costumes, crowns and wands. I ask whether the women know each other, to which he replies

“they are friends, good friends.” The play is for their school (for this is the space he understands the women to be in): pointing to the older woman in the middle of the group (the one with gray hair), he identifies her as the teacher. Bob has, himself, participated in and greatly enjoyed parties akin to this one. He sees no conflict, no tension, in the image – the women are happy and seem not to have a care in the world: this is an image of joy. From our many conversations over the course of the project, I understand his perception (and memory) of L. to be of a woman who was equally happy, content with herself: “She was a very happy girl.”

In our exchange on this day, I am reminded that Bob’s Christian faith is strong. While often shy, hesitant to put forth his thoughts and feelings, this reticence is seldom evinced when Bob speaks of his faith. Looking squarely at me, softly holding my gaze in his own, Bob says that L. “is way up in heaven with God”, a safe place, removed from all the violence and hurt in the world, and one to which he looks forward to going. Then, as if to alleviate the sombre tone, with a giggle he adds an aside - “at least she no longer has to pay taxes!” He considers this a moment and then tells me that the image makes him think of L. in heaven, dressing up, attending “parties like this”, and having fun. He repeats this many times; laughing and smiling, he seems lost to this thought and to derive great comfort from it.

I ask Bob how he might like to change the image. At first he is reluctant to alter the image in any way –he has no quarrel with it and, indeed, his very affection for the image as it is makes the need for such questionable. Pausing for a moment to re-consider, he proffers that, *maybe*, we could add some words, something that tells the viewer that the women in the image are happy – he quickly expands this to suggest the text address how people with intellectual disabilities are happy. It is, however, obvious to me that he is not yet satisfied. Pausing once more, he seems to reconsider and then tells me that what he would prefer is to have L.’s image somehow inserted

into the photograph – a visual realization of his (hoped-for) internal image of L. in heaven. Early on in the project, Bob had brought to the group an old photograph of L., one quite soft, frail and worn from Bob’s frequent touch. Sharing the image with me then, he had held and gazed upon it with even more gentleness and affection than he bestows upon the *Arbus* image today.

Presciently thinking he might wish to use the image in the project, Bob had requested I keep the photograph safe and hang onto it while the project was in process. In his attentiveness to (his memory of) L., he wishes now to make her present in a visual representation that is as faithful to L. as is possible.

Looking at this image^{xix}, the echo of L. in the one woman (the woman on the far right, identified by Bob) in the *Arbus* image is, to me, readily perceptible. With their relaxed bodies, gentle smiles, gaze directed at the camera (despite the one gaze being masked), both women project a quiet calm and composure, an impression of contentment and ease. Both have been photographed in seemingly familiar and comfortable surroundings – the woman in the *Arbus* image framed against a backdrop of trees, L. (I am told by Bob) posing on the backyard patio of the group home in which lived. The inclusion of the patio table, wind-chimes and plants succeed in giving the image of L. a “homey” feel, a sense of naturalness, bolstered by L.’s obvious comfort and happiness. Their inclusion work, in much the same way as the companionship of the other women and the costumes in the *Arbus* image, to suggest a social life, a life lived by L.. As Bob notes, both women have Down syndrome. Equally dressed in white, their clothes seem to fall across their bodies in a manner as relaxed as they themselves appear. Bob wants only to insert L.’s face into the image and he chooses to use the body of the woman second on the right, a position more central to the image. He leaves L. unmasked but does not, at first, say why: later he informs me that by doing so people will see her; they will know her (and, to my eye, will

know of his love for her). For Bob, no more is required and the image is, now, perfect.



Seeing the Photo-shopped version of the image, Bob asks Ted for a copy that he can frame and display in his home alongside his photograph of L.. Ted complies and, in addition, uses Photoshop to produce for Bob a less battered and cleaner copy of Bob's original photograph of L..

The Disabled as Me? No! Please, No...

Donna has been sitting quietly beside Bob as he and I work with the *Arbus* image. She has been listening attentively but, her interest and eagerness becoming visible, she now tries to surreptitiously catch my eye. Suspecting she has something to say, but does not want to intrude, I ask Bob if it would be alright for Donna to join our discussion. He warmly and readily agrees. For her part, Donna is quite concerned that Bob be comfortable with her participation – her initial reaction to this image was diametrically opposed to Bob's: she immediately slammed shut

the book containing the image and, turning her head away and tightly shutting her eyes, anxiously pushed it from both her vision and body. Bob had been witness to this, yet had responded much differently (as has been described), instead drawing the image close. Reassured by Bob that she has not interrupted him and that her difference of opinion will not upset him, Donna thanks Bob, many times, and turns towards me once again, anticipating my questions.

At this point, only Bob, Donna and I are left in the room. It is quiet, relaxed. Donna and Bob sit side by side, I am across the table from them – the image lies between us.

Ann: Why did you not want to work on this picture? Why did you have such a strong reaction to it?

Donna: I don't want to look at this picture! It's scary. It looks like a cult picture – they're all covered up, only their eyes are cut out of the mask. It's like the KKK [Ku Klux Klan] who insult people and argue and fight! They're violent people!

Her fear audible, Donna goes on at great length about the KKK. Gently (but firmly) blocking any attempts by Bob or I to speak, she tells us of a documentary on the KKK that she watched, late one night on television (and which she vividly recalls – content, colours, sound), and of other images she has seen, images which have her convinced that the KKK is evil. With much distress, she describes the “white sheets” that cover and hide KKK members’ bodies, the hoods with only holes for the members’ eyes. She spends a long time describing in detail the violence perpetrated by the KKK, the derision and intimidation they inflict. Confused by their hatred and prejudice, she nonetheless soundly denounces it. Throughout, she makes plain her fear and her dislike of this group that she understands to be terrifying.



Gently drawing her back to the image before her, Donna lets Bob and I know that the staging of the women in the *Arbus* image makes them far too similar to the KKK for her comfort. Consequently, the image terrifies her – as much now as when she first viewed it. Bob’s interpretation has done naught to alter her own. She is deeply disturbed by the association, referencing the white, flowing dresses and the masks (with slits cut for eyes) the women wear. Covered so completely by the costumes, the women are no more visible than are KKK members in their robes and hoods. Little in the image is exempt from comparison. The wands the women hold aloft remind Donna of the torches brandished by KKK members as they travel in the night, a contrast achieved in the image by the pairing of the white costumes with the darkness produced by the black and white photography. This association has the consequence of making these women with intellectual disabilities appear equally frightening and threatening. Throughout this project (although, interestingly, not in this instance), Donna has made frequent reference to being perceived, herself, as frightening consequent to (she believes) having an intellectual disability. Today, I am brought up short by her reading of the *Arbus* image, painfully reminded of her experiences, her feelings, her reactions to being so viewed by others and wonder why she does not bring it up here? Does the image strike too close to home? Is it beyond her capacity (or willingness) to acknowledge? Would it necessitate journeying too close to that which, today, is too hard to see?



As she speaks, passionately and emotionally, Donna's voice again rises dramatically, and she is responding to the image with her entire body: sitting bolt upright, angrily looking at Bob and I, hand slamming the table. She insists we not interrupt and, having experienced her reaction to being interrupted in the past, Bob remains quiet.

Donna has made no secret that she comes to this work from a background of persistent poverty, social isolation, and rejection by her family (most upsetting for her has been the rebuff by her siblings). She is acutely aware of being the only member of her large family with an intellectual disability. Stung by frequently hostile social experiences, she has history of reacting with aggression which only abets her rejection. Having a disability is critical to her identity and sense of self; a decisive factor in her estimation that people with intellectual disabilities are devalued and oppressed, and is understood by Donna to have directly and almost singularly caused all of her troubles. Viewing this image with this history, it is perhaps not surprising that she rails against the demonizing of people with intellectual disabilities that she perceives as being inscribed in the image – the image is a violent one, a violation certainly of her ‘truth’; the truth that such a perception is wrong.

Our conversation then wanders into different terrain: comparing interpretations, Bob and Donna confess to being surprised by the lengths to which their interpretations differ. What is surprising to me is that both regard the image as a good picture, a useful representation of people with intellectual disabilities and one which non-disabled viewers would do well to see. Not so unexpected is the revelation that their reasons for such diverge as radically as did their initial interpretations.

Bob believed the image told a good story about people with intellectual disabilities. By making this image available to non-disabled viewers, they would be able to see that people with intellectual disabilities are happy people; that they have friends, attend parties, and like to have fun. The image is evidence of that which is absent in the *David*, *Tracy* and *Blatt* images – a social life; a life lived and one worth living. Without explicitly articulating such, he indicates that people with intellectual disabilities are more similar to non-disabled people than dissimilar – we *all* like (and in this case, do) the same things. But I read more into it – by his demeanour, the surety with which he puts forth his interpretation, he seems also to imply that people with intellectual disabilities (at least those in this image) are at ease with themselves *as* people with intellectual disabilities. He appears content with his explanation, with L. and, right now, with himself.

In contrast, Donna believed non-disabled viewers would take away a far different (though equally valuable) message from the image:

People without disabilities should look at this picture and think about being in this position! How would they feel to be dressed liked this and called names?

For Donna, the image acts as an address by the disabled others in the image to the non-disabled viewers. She (and the others in the image) demands empathy from these viewers. She/they wants these viewers to put themselves (or be put by others) in this (her?) position, to “learn how it would feel to be these women and to be called names!” In this way, non-disabled viewers would come to appreciate how it feels to be teased or to be feared. She is angry. She is confused. She is sad. As she speaks, the depth of her emotion suggests she has returned to personal experience here and, sure enough, before long the conversation, again, returns to a recounting of the heartbreaking litany of experiences of ridicule at the hands of non-disabled

others, experiences of being regarded (like she feels the women in the image are regarded) as frightening, dangerous, and a threat.

Asking Donna how she might like to transform the image to put forth her understanding of it, she is, at first, very reluctant to contradict Bob. When I remind her that it is okay to have different interpretations, she lets me know that she strongly dislikes this image and that she desperately wants it changed. She first asks if we can remove the masks, the costumes, the stars on the shoes, the crowns and put the women in the image in “normal clothes” – “this would look better, *I would feel better if it was changed like this!*” What is important is to remove all references to the KKK – to people with intellectual disabilities as scary. I have to admit to Donna that this is likely far beyond the capacity of *Photoshop* and ask if she has any other ideas as to how to express the connection to the KKK that she read in the image. Wishing to assist Donna, Ted searches for and finds images of the KKK on the internet. Working with these images in another meeting, she arrives at her transformation of the original image:



Both Bob and Donna point to the presence of the masks worn by the women in this image. In a sense, they respond to the *Arbus* image from both sides of this mask. Regarding the masks as playful, Bob views them as little more than the means to a bit of fun. For Bob, the image of a group of happy women is a pleasing one, it makes him feel good. He is, likewise, pleased by the representation of intellectual disability that he reads in this image. It resonates and speaks to his memories, to his positive experiences and understandings of intellectual disability (and his own moments of ease with it), and to his love for L.. In this image, Bob does not see intellectual disability represented as tragedy – nothing, in fact, is tragic about this image, not even that it precipitates a conversation about L.'s death for this image provides Bob with a satisfying vision of L., in heaven, having fun at a party like this. His transformation of the image changes little in the original and, for Bob, remains faithful to the story of the image. It serves only to strengthen and concretize his personal connection to it, to make present and to open up to the viewer his feelings for L..

Donna regards the mask in a radically different way – the masks work to construct the people with intellectual disabilities in the image (and, by extension, all people with intellectual disabilities) as the embodiment of evil, a frightening other to be avoided at all costs, and who evoke condemnation by non-disabled others judging them. The image speaks immediately to her experiences of being perceived by others as scary, as threatening, and someone to be shunned as a result. It evokes an understanding of self that is lamented, to be resisted and even feared. Unable to remove the signifiers of evil (the masks, dresses, and wands), she chooses instead to exaggerate the association as a means of making plain what is to her the image's explicit and pathologizing message; to tremble that which is so readily taken for granted. The darkness of the original works in her favour. In that the masked women in the image are staged in such a way

as to appear to be holding the image of the KKK, and to be simultaneously staring back at the camera/viewer in a sombre and solemn way (despite the smiles), the transformed image also works as a demand for empathy, for learning, for new understandings and as an address in another way – as accusation (of the non-disabled viewers’ responsibility for these visual constructions of people with intellectual disabilities, and for the demeaning and dehumanizing attitudes that both lead to and are reinforced by them). Discontinuity, the disruption of heretofore uncritically digested assumptions about people with intellectual disabilities, is effected by this change.

The Disabled as Me? Yes! No! Maybe...



The group’s final transformation of the *David* image emerges over the course of the project as opposed to resulting from any single discussion. The initial idea for the change comes from Robin and is prompted by the group’s first discussion of consent. Insisting that David is an adult, that his permission has not been sought for this image, and that he would be terribly embarrassed by his nakedness being made so public, Robin considers many different presentations that he feels *David* would prefer – all involve dressing *David* – “he needs clothes” - and removing him from the mattress – “put him in a better position”. Without clothes, *David* is

bare, has a bare life, and is barely living. For Robin, Donna, Sam and Bob, the addition of clothes is one solution for they believe clothes imply a social self, active participation in a social world, in life. The group often talks about *David's* age, about what he should or would prefer to be doing if given the choice. (While never explicitly stated, at times these discussions hint at what *David* could be doing were he not so disabled.) Robin, Sam, Bob and Donna often return these conversations back to consideration of the importance of clothes to how one is perceived and received by non-disabled others. Most often, they come around to an expression of how *they* would like to be portrayed. Speaking for *David* from their own positions as people with intellectual disabilities, the assumption seems to be that *David*, as a person with an intellectual disability, wants what they want. The general flavour of most of their dialogue is upbeat. Yet there is a sense that they are seeking to reclaim this image, to rework it to present *David* differently – not as tragic, but as valuable, as a person deserving of recognition and respect. Moving closer and closer towards *David*, they make plain their sense of responsibility to him, their non-indifference to the real man they perceive to lie behind the image. *David*, over the course of the project, has come to concern them very much and each transformation has been understood by them to be a demonstration of their un-refusable obligation to him. Unable to effect any real change in the life of the man in the image, they exercise their responsibility/response-ability towards him through these many transformations. In this phase of the work, they stress, repeatedly, that there is nothing wrong with having a disability.



In their discussions of ways to alter the image, the group never lands on a single idea. In response, Ted takes their multiple suggestions and creates a number of possibilities in preparation for a presentation the group was making. Above is the transformation that Donna, Bob, and Sam agree upon – in that he did not participate in the public presentation, Robin was not present when this decision was made but he wholeheartedly endorses this re-imagining of *David*. Donna, Bob, Robin and Sam like this re-working of the image; they feel it puts forth a positive image of people with intellectual disabilities. There is the sense that dressing *David* in such a ‘manly’ fashion works as reversal, to undo the stare that comes with looking “different” for no-one would look askance at him now. Interestingly, *David* is not, himself staring back at the camera (as the group was concerned to have *Rosie* do, for example) – he continues to look off to the side, however, whereas Donna, Bob, Sam and Robin interpreted the averting of his gaze in the original image as a sign of his embarrassment, here it appears almost haughty.

I understand them to be trying to show that *David* is okay as he is, that he can proudly ‘stand’ on his own as a person with a disability – this is an attempt to celebrate *David* and themselves. But, to my eyes, the changes also reflect their discomfort (a discomfort shared by general population)

with people with very obvious and severe physical disabilities – with atypical bodies, and/or their adoption of or inculcation into dominant ideas of what is ‘normal’, ‘acceptable’, ‘beautiful’, and ‘desirable’. Throughout, the discussions are peppered with the word “normal” – they want *David* in a more “normal” position, doing more “normal” things and, indeed, in making him the “same”, they would seem to be enfolding *David* up in their own terms (and those of the dominant discourse). The limitations imposed by *David*’s impairment do not figure in these discussions, and, once again, they seem to be speaking *for* him from their own positions as people with intellectual impairments but *not* as people with additional physical impairments that would negate the possibility of independently standing. This tension, the im/possibility of their accruing to *David* value as he is, is, I believe, revealed in this last exchange about the image, an exchange leading to the final change to the *David* image. In this fragment, they once again recaption the image.

Ann: Okay, so then we have the [transformed] picture of David which, unfortunately, Robin you did not see this. But the rest of you should remember from the presentation....Does it need words and, if it does, what words? What do you think?

Robin: It means...

Ann: Because, again, the story you wanted to tell again is that you wanted him in a more normal position, looking more normal and standing straight and tall. What words do you think?

Sam: I am trying to come up with some words.

Robin: I am trying to come up with some words.

Robin: Fantastic? Gorgeous? Or...

Ann: If you see a picture of a good looking guy up against, and dressed really nice, what would you think? What do you think that really means, looking nice, standing up tall?

Sam: Maybe something like, such and such, or would I have to give an example of a name, such and such means, handsome attractive, fantastic?

Ann: We have handsome, attractive, and fantastic; let me put them down so we don’t forget.

Robin: Or decent.

Sam: Or glamorous. Decent is okay.

Ann: We have glamorous, decent...

Robin: Mature.

Ann: Mature.

Robin: Yeah.

Ann: Mature is an interesting choice because you guys all thought he looked like a baby. Which one do you like? Or, what we can do is that Ted can do it with all those words and you can decide which one you like best.

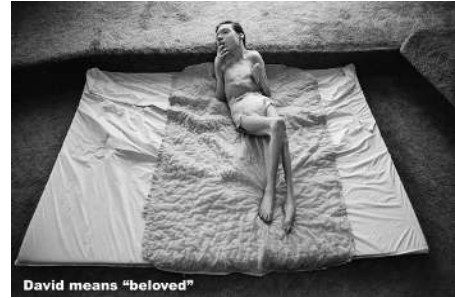
Ted then creates new images with these different captions underneath and the decision is made to use “*David* means fantastic” – no explanation (beyond that they “like it best”) is offered. Their choice of adjective, I believe, effectively reflects their opposing conclusions regarding *David*: “fantastic” as he is? “fantastic” when he looks more like us/normal?

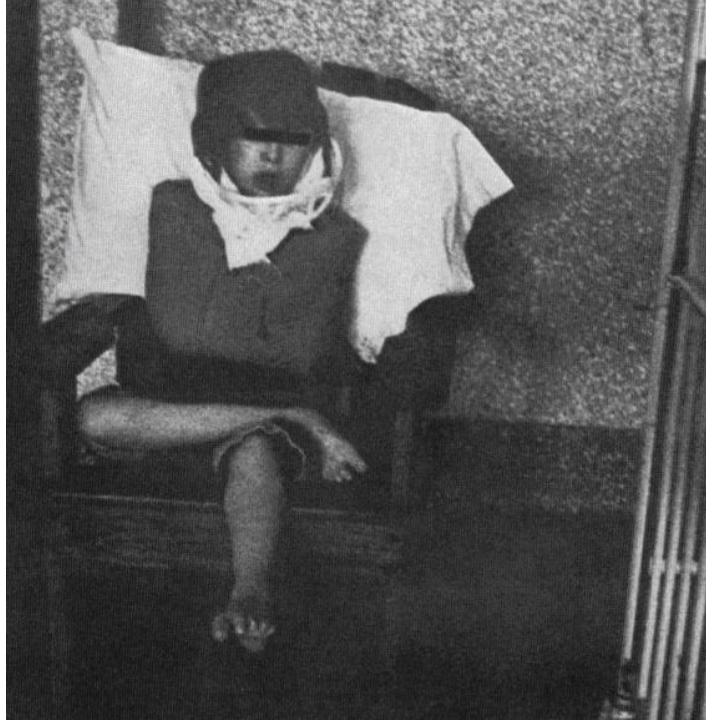
Ann: Alright, we can officially put *David* away.



Chapter 12 – Re-imaginings and Re-imaginings

In the pages that follow, I have laid out Sam, Bob, Donna, and Robin's transformations of the original images. As a pictorial summary, original images are placed alongside the new ones, making immediate their critique, their feelings and thoughts about each one. The images are further grouped in a manner intended to reflect the group members' conversations, their movement back and forth between different images, the ways in which, for them, the images spoke to or of each other. These re-imaginings make visible non-disabled imaginings of intellectual disability – the stories Bob, Sam, Robin, and Donna feel the original images tell – and also reveal their own visual re-imaginings; the different stories, and political statements, they believe could and should be told through photographic re-imaging.







Foster mother Lori Olivier takes care of 8-year-old Martha Katsouris as she has a specific episode in the mental room in Toronto during a fight for treatment. Martha has cerebral palsy.

Foster mother Lori Olivier gives life, where Robert Latimer took it
Who Tracy might have been








What's wrong with this picture?

You'll find the clue in those innocent faces. They tell you that these people can't possibly understand this most important challenge — living with dignity in our community.

The York Central Association For The Mentally Retarded helps developmentally hand-capped people meet this challenge everyday. Through residential programs, parent relief, recreational activities, and foster care programs.

Our challenge is to help the Association keep its services going. Money is all that stands between giving mentally handicapped people a healthy mix of life experiences and the isolation that will come with a lack of funding.

Let's keep the picture bright. Give them the support they need to help themselves. The United Way's 1985 drive for funds is now underway. The York Central Association For The Mentally Retarded, along with 26 other member agencies, is depending on you.

It's your United Way. Let's keep it working.

For more information on the programs offered by the York Central Association For The Mentally Handicapped call, (410) 864-8117 or (410) 869-0209

C'mon, cut it out...Now

Name _____	
Address _____	
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State _____	
Zip _____	
Amount of my personal giving _____	
\$10.00	\$25.00
\$50.00	\$100.00

Send to: United Way, 225 Market Street, Box 9, Westport, Oregon 97143
For more information call (410) 869-0209

GIVE!



United Way
of York Region



FOUR CHILDREN FOUND IN ONE CLASS



Although there are eight years' difference between the youngest and the oldest, all four children possess the same mental age. It is a mistake to attempt to educate them in the same class.

The Canadian National Committee for Mental Hygiene stimulates the organization of special classes for the mentally retarded.

FOUR CHILDREN FOUND IN ONE CLASS



Although there are eight years' difference between the youngest and the oldest, all four children possess different abilities. It is a mistake to attempt to educate them in the same class. All children need an individual program.


A HALLMARK HALL OF FAME PRESENTATION


ROSIE O'DONNELL AND ANDIE MACDOWELL

Riding the Bus with My Sister

Inspired by a true story

They've always been family...
but can they be friends?



 SUNDAY, MAY 1, 2005 ON CBS
THE 224TH PRESENTATION OF THE HALLMARK HALL OF FAME

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(Un)Wounding Representations

Section 3 – (Un)Wounding Representations

Chapter 13 – The Right of Inspection

Introduction

It concerns legitimacy, one's *entitlement* to look, to arrange or hold within one's gaze, to take in a view, or to "take" a photograph – hence it concerns the title, *droit de regards*.

(Derrida, 1998:2)

I don't understand why you took *that* picture, this is so embarrassing, um, you had no right to do that. If you wanted to do me a favour you wouldn't, um you would appreciate my point and you should have asked before you did what you wanted to do, or so, and I would have given you my answer and you would definitely make your decision about what I say and then do what *I* please and bear with it, you know!

(Sam, *Weightless*)

As an entry point into speaking to Sam, Bob, Donna and Robin's work with the images, this chapter concentrates upon the question of the right of inspection, the right to 'take' a picture. The mechanical act of photography is a lesser consideration here: what assumes urgency in the space of this project is attention to Sam's outraged query: "I don't understand why you took *that* picture", why you told (chose to tell) *that* story; his inference as to the impacts of *that* picture; and his equally strong assertions that "*you*", the non-disabled photographer and viewer, had no right to take it.

The group members' thoughtful musings over visual imagings and imaginings of people with intellectual disabilities forcefully take up the questions posed in this research project: "Who has the right of inspection over public photographic images of people with intellectual disabilities?", "What stories are thus told (and not told) about people with intellectual disabilities in the reading of these public photographic images?", "Who should possess this right of inspection?", and

“What happens when this ‘right’ is given to people with intellectual disabilities themselves?” As I have noted, these questions are influenced heavily by Derrida’s (1998) thesis on the “right of inspection” of photographic images.

Important are Derrida’s and the group members’ ethical concerns regarding ‘entitlement’: control over visual representation and meaning-making; over inscriptions and what the viewer is given-to-be-seen (Silverman, 1996); the disciplining or (conversely) multiplicity – the im/possibility –of just what is (can and cannot be) seen. A rationalization for such is amply provided by the literature on visual representations of disability and bolstered by social work emphases on social justice and giving voice (I refer the reader back to chapter 4). At this juncture in the work, my movement into the group’s engagement with these questions and concerns is further abetted by Walter Benjamin’s *Theses on the Philosophy of History*, articulated in *Illuminations* (1968), on the necessity of writing history from the perspective of the ‘defeated’ so as to disrupt the ‘triumphalist’ (‘triumphalist’ being here synonymous with the ‘ableist’) gaze, and I borrow heavily from Baer’s (2002) application of Benjamin’s thesis to a re-reading of a collection of photographs of Jews in the Lodsz ghetto taken by Genewein, a senior Nazi bureaucrat of the ghetto. In a critical re-thinking, a reading of the photographic images turned against the source, Baer is concerned to call into question the perspective of the Nazi victor/producer recorded in such visual documents and records of the ghetto as a means of trembling that which we think we know. As was articulated in the introductory chapters of this thesis, photographic imagings and imaginings of people with intellectual disabilities have remained static and one-sided – told and read almost exclusively from the more powerful ableist perspective. Revealing much about how they are understood and their consequent overall lack of power, people with intellectual disabilities have, thus far, been excluded from both photographic

subject positions, with (for them) disastrous results. Turning their own readings against the ableist source of photographic representations, Sam's, Donna's, Bob's and Robin's work, in the same way, "corrode(s) the comforts" of common understandings of intellectual disability (Baer, 2002:128).

Drawing on Derrida, Benjamin and Baer, this chapter begins with an exploration of the group's recognition of and responses to being denied 'the right of inspection', their awareness of being relegated solely to the position of 'viewed', looked at by non-disabled others. I move then to reflect on what unfolded when Sam, Bob, Donna and Robin were asked to take up the right of inspection. Weaving in the theories of Cixous, Garland Thomson, and Barthes, I consider their shifting positions – in some moments positioned as viewers, commenting on the photographs, and in other moments positioned as watched, viewed, inspected themselves; sometimes distanced from the people with intellectual disabilities in the images, and sometimes (dangerously) identifying with them. I also consider what they saw, what they noticed about the photographic images they worked with and how what they saw mattered to them, from these various viewing locations.

I wrote a few sentences ago that Sam, Bob, Donna and Robin 'were asked' to take up the right of inspection. It was, of course, me who did the asking. This is no small thing as Robin, Bob, Sam and Donna have never before been asked for their opinion on visual representations. This invitation, the positioning of the group members as the ones entrusted with the right of inspection, is something new for them and, once given, cannot be taken away. Expanding on his question of who has the right of inspection, Derrida (in the seemingly Benjaminian language of the victorious subduer) wonders "who has the right to watch the scene, to "capture" the images, to interpret them, frame them and edit them? Who has the right to invoke narratives?" He ends

this piece of his wondering provocatively by posing an additional question, one which, over the course of the project, is revealed to be of particular relevance to the group's work: "And [who has the right] to be believed?" (Derrida, 1998:8).

The Brutality of the Victors: Denied the Right of Inspection

Lippard (2003:345) details how certain photographs imply "a dialogue, an exchange, an I/eye (the photographer) and a You (her subjects, and we the viewers...)." Lippard, in this instance, is speaking to her viewing, from a distant cultural space and time, a historical photograph of a Native family, taken by a white female photographer; addressing the tensions inherent in production, seeing and knowing – in photography as communication. This image, as both example and contradiction of colonialist imagery, she finds particularly appealing, and her essay is an exploration of her relationship with it, her efforts to understand the dialogue that took place at the point of its creation and that which may now be possible between the photographer, the subjects, the (contemporary) viewer and the image itself.

Grappling with these same concerns, Sam and the other group members draw urgent attention to the absence of dialogue between the photographer and her/his subjects in disability imagery. The photographer has done "what [s/he] wanted to do"; s/he has not "asked before [s/he] did"; s/he has not taken into any account, the words of her/his subject; s/he has done entirely as s/he pleased. They can detect no attempt at 'dialogue' in the visual representations of people with intellectual disabilities: this having been replaced with speaking about, around, and over. Any possibility for 'exchange' is one which effectively excludes them and all people with intellectual disabilities. Their emphatic insistence on the necessity of consent to visual imaging; admission of how the people with intellectual disabilities in the images (and, indeed, they themselves) would worry about how the images would be (mis)used; and caution/reluctance/refusal to admit their

own images into the public realm all testify to the surety of their exclusion from this dialogue, to the denial of their right of inspection. Positioned only as ‘viewed’, as ‘looked-at’, even the elemental notion of people with intellectual disabilities as being in a position to inspect, comment, grant or withhold consent never enters the dialogue. Barred from this space of dialogue, the right of inspection has thus been usurped by non-disabled others who assume the right of inspection over/of people with intellectual disabilities. Benjamin (1968) warns that one must never forget the brutality of the victors. If what we know derives only from perspective of the “triumphant”, a conqueror dictating the terms upon which the victims can be seen, can be known, remembered or forgotten, then the perspective(s) of those who have been “defeated” can never be recalled (Baer, 2002:128). These lost (and at risk of being lost) perspectives, must be made visible and must be preserved if we are to unsettle “the terms on which our understandings of ourselves and our world are based” (Simon, 2000:13). The group members’ work with the images suggests that the “conqueror’s legacy” (Baer, 2002:128), the brutality of these public photographic images, is a function of three things that connect the right of inspection to this notion of dialogue, of exchange: these social representations are not about them, nor do they address them, and more, they do not permit them to respond.

Not about them.

Moving into this project, I really did not know just what the group members might see when they looked at these images. It very quickly became clear that what Sam and the others see inscribed in most of the images they worked with are the popular and persistent un-truths of intellectual disability. Buttressing much critique of disability imagery, these public photographic imagings are not really *about* them, not about people with intellectual disabilities, for they are no more than conventional tropes of disability, dys-functional stereotypical imaginings rooted in an un-

knowing that perpetuates misunderstandings. It is then, an im/possible capture (Bal, 2004) purporting to reveal the ‘truth’ about intellectual disability. The more powerful ableist perspective may control disability representation, but fails (or refuses) to ‘capture’ the being/Being photographed subject. As Donna declares, non-disabled people fail to “understand where we’re coming from”. Sam and the other group members speak, for example, to Garland Thomson’s notion of how, for the non-disabled producer and viewer, “shape structures story” (2007:113). This, I feel, is a useful construct for articulating the group members’ understandings of the staging of some of the original images they work with. Some images, by accentuating and attenuating the impaired body/body with impairment (e.g., *David, Tracy*), enable the tenacious belief that “the configuration and function of our human body determines our narrative identity, the sense of who we are to ourselves and others” (Garland Thomson, 2007:113). For the non-disabled viewer, the evidentiary power of the disabled body is thus confirmed: anomalous bodies “always tell the truth” (Gilman, 2005:85). Held captive to hegemonic mis-understandings (and captivated by them?), non-disabled viewers have little incentive to question or move beyond what they are given-to-be-seen. As the group members make plain, “shape” determines the stories told, dictates what can be said. But I find that, for Robin, this wanders into somewhat different territory. While he explains the preponderance of violently stereotypic photographic imaging as stemming from a not-knowing – “they think they don’t know him” – he comes, in time, to qualify this further. Pointing to ‘intellectual disability’ as a, if not unique, then extreme case, he defines this not-knowing as a deliberate and irresponsible un-knowing, possibly even a casually discounting, discarding choice to un-know; a choice which carelessly, indifferently, unthinkingly, portends the impossibility of knowing.

The influence of the well-documented ableist prejudice on non-disabled visuality and the “scopic

regime”, the cultural construction and conflation of looking, seeing, knowing and telling (Rose, 2007:2-3) that determines the non-disabled viewer’s reading of public photographic images of people with intellectual disabilities is, to Bob, Robin, Sam and Donna, apparent. Their reading of the staging of the *David* image is the most powerful example that springs to mind. They are painfully aware of how the obvious (even exaggerated) frailty of his body and his apparent abandonment inevitably bring about the common responses of pity and dismissal as lesser and unknowable. (Yet, they themselves know no-one who looks “like that”.) I am also reminded of their many conversations about the *Tracy* image, their unshakeable belief that the intention of the producers was to make certain the viewer of the image understood that the girl had something wrong with her – the sizing and foregrounding of the wheelchair, the posing of her body, guaranteed the viewer would tell themselves this story and no other. These are the rules governing the viewer’s looking at this image (Derrida, 1998). And, in this case, they discover that these same rules hold true for the *Rosie* image. The non-disabled body of the actress, Rosie O’Donnell, is photographically disabled, staged as to suggest intellectual disability, thus demarcating the parameters for its reading. Visual conventions of intellectual disability are inserted into the image (for example, the “dreamy” look, mismatched and child-like clothing, open posture), applied to the actress portraying a character with an intellectual disability, and then opposed by the more sophisticated and restrained look, attire and posture of the non-disabled/abled character/actress also in the image. This “mutually amplifying juxtaposition” draws attention to these cultural markers of disability and ensures the viewer’s frame for reading the body as disabled (or as pretending to be) (Elks, 2005:275).

For the group members, this insistent and reductive reliance on ‘body’ to tell ‘story’ is wrong. The brutality of these images lies in how they succeed in foreclosing other narratives, other

understandings such as their own and, in the absence of the voices of the intellectually disabled subjects of the images, those understandings that they suppose for them. “It doesn’t tell the whole story” (Bob); it is not really ‘about me.’ Confronting what Baer refers to as the “apparently total correspondence between the (non-disabled) photographer’s perspective and incontestable authority” (2002:131), the group members insist that there is an other to the plot, to the story of intellectual disability framed within the images the group chooses to work with – one that works to unravel or disrupt the ableist plot. This “untellable that the image declares” (Derrida, 1998:1), this forbidden (and thus untold) narrative is, for the group, explicitly *their* narrative, a story “about me.” It is this they tell me that is so very important. Their (visual and otherwise) autobiographies (and those of the people with intellectual disabilities captured in/by the images) have, to date, been missing from any ‘dialogue’.

Not addressed to them.

Positioned now as the ones who look, the group members have much to say about how others in the viewing relationship might perceive the images. The group members are repeatedly struck by the tremendous divergence between (what they understand or suppose to be) non-disabled perceptions to the images and those of people with intellectual disabilities. The majority of the images are so far removed from what they themselves would put forth as disability representations (and from what they are certain the people with intellectual disabilities in the images would want) that Sam, Robin, Donna and Bob have little doubt they were not the intended audience. The sureness with which they pronounce that *David and Tracy* would be embarrassed to have been photographed as they were; Donna’s equally strong belief that the women in the *Arbus* image would have been horrified to have been staged in such a manner as to provoke an association with the KKK; and the group members’ incredulity that anyone could

find a child as frightening and dangerous as the *Blatt* image intimates demonstrates this. For the most part, this does not surprise me. Given my awareness of their status as self-advocates, neither am I surprised by the extent of their engagement with the full text of the *United Way* image; in particular, the producers decision to use the word ‘retarded’. This is a word violently opposed by Sam, Donna, Bob, Robin, and self-advocates more broadly; one at the root of much ongoing (and heated) debate. For Sam and the others, if the image and text had been addressed to them, the authors, surely, would have selected an alternative word. In that it wasn’t they conclude that the images are structured towards a particular audience and the telling of a very particular and determined story – “(R)emain within these limits, this frame, the framework of these frames...” (Derrida, 1998:1) – how else can one explain the divergence of stories told by people with and without intellectual disabilities?

Responding to what they perceive to be the objectification and dehumanization of people with intellectual disabilities in these public photographic images, Sam, Robin, Bob and Donna are convinced that the images are singularly addressed to a non-disabled viewer, a non-disabled viewing ‘you’ (Lippard, 2003) whose expectations and understandings are embedded in and shaped by cultural conventions and institutions that authorize some readings while erasing or forbidding others (Kratz, 2001). The (non-disabled) viewer has a desire for “unambiguous distinctions” (Baer, 2002:136) between their ‘normal’ self and the ‘abnormal disabled other’ in the image and, framed from a normative scheme of intelligibility, an ableist aesthetic, the original images fulfill this desire and thus interpellate the non-disabled viewer in a particular way (Darke, 1998; Garland Thomson, 2001; Hevey, 1997). Garland Thomson (2001) articulates the typical types of relationships with the viewer that photographic representations of disability habitually seek to establish: ‘ordinary’ spectator looking at images of ‘extraordinary’ people with

disabilities, benevolent able-bodied spectator who rescues the disabled object of the images, and non-disabled tourist voyeuristically consuming the ‘strange but true’ disabled other. In that Bob, Robin, Donna and Sam were not the intended viewers, but are the ones who are looking, these relationships crumble here.

At play then are chosen viewers looking at chosen images, the “ones that are wanted” (Kratz, 2002:1): photographs confirming an opinion of people with intellectual disabilities already held in common by the viewers (Sontag, 2003) and permitting only a telling of disability as tragedy, as frightening, as undesirable. “Look, the photographs say, *this* is what it is like” (Sontag, 2003:8). With few exceptions, these are the stories the group members believe the producers of the image want told and the stories which non-disabled viewers would choose to tell themselves about people with intellectual disabilities should they encounter these images. These are the stories that keep being told, that are never disrupted. Underscoring the falsehood, the instability of the desire for unambiguous meaning, the group members’ make plain how viewing is a matter of perspective. It is also a matter of position and privilege. Because, for the most part, they themselves (as people with intellectual disabilities) see the images only as un-truths, and because they are similarly convinced that the disabled subjects of the images would strongly dislike these images and would tell vastly different stories, Sam, Bob, Donna and Robin do not believe themselves to be (or even to have been considered to be) an audience, a viewing subject. What I find most poignant is that Sam goes as far as to suggest that it likely never even crossed their minds to ponder the possibility.

Does not let them respond.

Garland Thomson (2001:338) writes that photography provides non-disabled “viewers with an immediate yet distanced way to contemplate the disabled body without actually having to expose

themselves to visibly disabled people”. Keenly aware of the aversion of many non-disabled others towards people with intellectual disabilities, what assumes tremendous importance to the group members is this realization that it likely never enters the consciousness of the non-disabled producers of these images to consider the perspectives *of* people with intellectual disabilities *regarding* the images: to seek consent for the taking of their photograph, to solicit their opinion, to give credence to their critique. (It should be noted that, to date, even much of the larger disability community – academics and researchers included – is similarly guilty of this exclusion.) This concern moves beyond the question of address and the invitation of response typically engendered within an address. And, while the issue of consent is revealed as critically important to the group members, it seems to me to push beyond a matter of consent as well. It strays instead into their forceful exclusion from the space, the activity, and even the possibility of response, of dialogue. More than a discounting of what it is that non-disabled others hear people with intellectual disabilities say, more than a refusal to hear what they say, this is an actively dismissive attitude that does not believe they are even capable of saying. From this perspective, people with intellectual disabilities can only ever occupy the position of ‘looked at’. Their coming-to this knowing is a painful process; as self-identified self-advocates they react as if to a slap across the face. I am prompted here to recall Donna’s emotional recounting of how the consent procedures used in this project were in stark contrast to her many hurtful experiences of having people take her picture or do something that directly affected her without ever asking her permission or speaking to her about it. And to how all of the group members adamantly insisted that the consent of people with intellectual disabilities must always be sought, irrespective of the severity of the disability, even as they bemoaned the (im)possibility of this ever happening.

Speaking to the positioning of the subject and the viewer of a photographic image, “the pose, position, supposition, the place of each *subject*”, Derrida (1998:3) articulates what I find to be a useful movement for an understanding of Sam’s, Donna’s, Bob’s and Robin’s concerns regarding the violence of these visual imagings and imaginings and of questions pertaining to the right to inspection and response. Aligning strongly with critiques of disability photography, the performative function of the public photographic images of people with intellectual disabilities is vividly enacted through this moving positionality. It begins with the imposition of a pose – the imposition of a dysfunctional and reductive pose upon the labelled person inside the framed limits of the image. This then is contrasted with the more freely chosen pose of the non-disabled viewer outside (and thus free of the constraints imposed by) the image’s borders. (In each of the images worked with in which there is also a non-disabled subject, the ‘pose’ of that subject is that of a ‘normal’ adult, a pose diametrically opposed to that of the intellectually disabled subject.) Positioned inside the image – as ‘looked at’ but not ‘looking’ – people with intellectual disabilities are restricted from speaking. They are positioned as a non-viable speaking subject (Butler, J., 2004), limited to a visual but not an aural presence.

The non-disabled viewer, by contrast, remains outside the frame, charged with capturing, with making meaning and with telling/speaking about the image and the persons with intellectual disabilities held captive within. Looking beyond the physical space or position of the viewed (inside) and viewer (outside), the opposed/oppositional binary ‘position’ of each is cemented: un-able (dis-abled) object/spectacle and able(d) subject/spectator. Both pose and position rely on widely divergent suppositions regarding ability. The in-ability of the disabled subject of the image to have an opinion, to be able to look, regard or consider, or to have the facility (let alone the desire) to respond is opposed to its other – the capability ascribed or attributed to the non-

disabled viewing (and speaking) subject. According to Derrida (1998), it is the combination of these elements that keeps viewer and viewed ‘in her/his place’. And, as the group members articulate, the ‘place’ established as appropriate for people with intellectual disabilities is a violent one – ‘jail’ for the child in *Blatt*, an institution or worse (abandoned to the elements) for *David*, *Tracy*, and the women in the *Arbus* image. Connecting the group’s work then to critiques of disability imagery, this place is, however, not restricted to the spatial place of each in this viewer/viewed dyad but moves beyond to both reflect and perpetuate ‘place’ in the larger scheme of relations between people with and without intellectual disabilities (Garland Thomson, 2001; Kitchin, 1998). This is a conclusion the group members grasp quickly. As Bob once asked, “Why don’t they [the photographers] show pictures of people with disabilities being part of groups and speaking at conferences?”

As articulated by Lippard, in her aforementioned essay on colonializing photographic imagery of Native Canadians (2003:346), photography is employed as “a tool by which to exploit and disarm”, to keep people “in their place” and “to make them objects of study and contemplation”. As used by non-disabled ‘conquerors’, it invites staring at the disabled object/subject of the image (Garland Thomson, 2001). The violence perpetrated by the images is to turn the people with intellectual disabilities subjected to it into a ‘thing’ (Sontag, 2003). Nothing changes, the ableist perspective triumphs and, in the eyes of Bob, Robin, Sam and Donna, these images are violent. Returning here to consideration of photography as a possibility for dialogue, as a “machine for making talk” (Derrida, 1998:3), earlier in this chapter I referenced Derrida’s question as to who has the right to be believed. But Donna, Bob, Sam and Robin demonstrate an astute awareness of the prematurity of Derrida’s question for people with intellectual disabilities: before the question of belief can be addressed, there must first be an understanding that people

with intellectual disabilities *can* and *want* to ‘talk’, to respond, *and* that they have something to say.

Taking Up the Right of Inspection

What they see.

In her work on images of atrocity, Sontag (2003:7) cautions us always to consider who are the “we” to whom images of violence are directed, and who is the “we” who is looking. Non-disabled producers and viewers of visual images of disability may presume a hegemonic non-disabled audience but “(n)o “we” should be taken for granted when the subject is looking at other people’s pain” (Sontag, 2003:7). Taking up the right of inspection, Sam, Bob, Donna and Robin are a ‘we’ not taken for granted, seemingly not even imagined, by the producers of these images – and, they are looking and are seeing otherwise.

Looking at these public photographic images, what the group members see most profoundly is the perspective of the non-disabled/ableist ‘victor’. I appropriate Benjamin’s language here to mark Sam’s, Robin’s, Bob’s and Donna’s immediate recognition of the power differential between people with and without intellectual disabilities apparent in these images. It is these non-disabled producers and viewers of the images who “haunt the threshold of the [group’s] encounter” with the images (Lippard, 2003:344); their ‘eyes’ which determine who can and cannot look, what can and cannot be seen. It is this destructive and self-enhancing ableist gaze that writes onto the body of the person with an intellectual disability captured within the image’s frame (for ‘captured’, ‘trapped’ is how they understand it) dysfunctional narratives and, in doing so, writes away the stories, meanings, and signature of this particular person with an intellectual disability and other labelled people more generally. The said of the images is the common language of intellectual disability: different, lesser, unable, unknowable. In Derridean terms,

they understand photographic imaging of people with intellectual disabilities to be no more than the ‘invention of the other’ (1998). It is naught but the enfreakment of people with intellectual disabilities that reduces them from a ‘who’ to a ‘what’, someone no-one would ever desire to know, someone whom no one wants, something no-one would ever hope to be. Mis-taken, constructed in multiple scary, undesirable, and inaccurate ways, the ‘real’ person with intellectual disabilities captured in/by the image is thus stolen. In this way, her/his body is marked, erased, used via the sensationalizing, stereotyping, and objectifying typical of media images of people with disabilities (Clare, 2009); “ruined” in and through these public visual imagings and imaginings (Vaughan, 2010:191). They understand that in the apparent refusal to see otherwise, this powerful ableist gaze acts as a veil to prevent the non-disabled from seeing what Donna, Sam, Robin and Bob vehemently argue “they ought to be able to see” (Cixous, 2001:3): “for [ableism] has little claws, it holds the eye under a little tight veil, screwed down eyelids, insinuations...” (p.12).

Equally compelling, is that Robin, Sam, Donna and Bob see, not welcome, not the extending of hospitality, but primarily expulsion, abandonment, segregation, containment. Foreclosed is the possibility for connection, for attempts to know. The images effectively work to establish distance; to put space between the ‘looked at’ disabled subject/object of the image and the non-disabled ‘looker’. And while the group believes this disadvantages both, they also stress the very real dangers this poses to people with intellectual disabilities.

They come to see, too, the extent of their exclusion from visual representation, their relegation to the constricted position of ‘looked at’ – “for the other, even when not an enemy, is regarded only as someone to be seen, not as someone (like us) who also sees” (Sontag, 2003:72). They are denied other subject positions in the viewing relationship, denied the right of inspection – a right

which has, instead, been assumed by the non-disabled producer and viewer. Without the power afforded by the right of inspection, for people with intellectual disabilities public photographic representation is reduced to a condition of impossibility. It is interpreted by the group members to be violent, not just because it shows them violent things but because “it fills the sight by force” (Barthes, 1981:91). The impact of the images on the group members is undeniable: they flinch, they recoil, from the force of what is inscribed in these images. Barthes adds another element to our understanding of the violence of the images: that the viewer has a sense that nothing in it can be refused or transformed (1981). At times, (possibly quite often) this is something that the group also sees and reacts to: their feelings of ‘weightlessness’ as regards their ability to push back against these inscriptions, to effect change.

How they look.

In coming to understand/reflect upon what happened when Sam, Donna, Bob and Robin were, in this project, given the ‘right of inspection’, I am drawn to consider not only *what they see*, but, also, *how they look*. This looking is a new (for them) looking, a new way of seeing as this task that I have assigned them is an unfamiliar one: they are coming to this with, I think, an unknowingness and yet with an openness. As an unfamiliar task, they know not what to expect, nor (with any certainty) what is expected of them. (I share this uncertainty - neither did I know what would happen and, like them, I am excited albeit unsettled by it.) Yet they willingly take up this new “reading position” (Cixous, 1993:31), this new relational space and they sit before the images, before me, before each other with open faces, open eyes – an openness to seeing what happens.

Quickly laying to waste dominant (‘expert’ and lay) misconceptualizations of their intellectual (in)ability, they reveal to me the tremendous sophistication of their reading of the images. Their

words and work, as laid out in the preceding chapters, echo the critique offered by Derrida: “they [the images] pretend that they are showing us the thing itself” (2001c:45). Their attention to the staging of the images, recognition that each image was a choice made by the producers of the image, discernment of the reasoning and intent behind these decisions, and the im/possibility of the truthfulness of each image all make evident their awareness of the absence of neutrality or ‘innocence’ in the photographic images they chose to work with.

In this (and I am referring, in particular, to their initial) apprehending of the images they appear, at least in part, to be viewing from a distance. As their eyes ‘take in the view’ (Derrida, 1998), sweep across their paper copies of the photographs, focusing on and capturing particular details, they begin (tentatively at first, then with greater confidence and, eventually, with an element of horror) to critically assess how the difference of disability has been constructed in the images. Their early looks strike me as a more, if not objective then certainly detached look in which, as ‘spectator’, they approach the work as critical observer, as a called-upon (by me) commentator. Well apprised of the intent of the project (to learn how people with intellectual disabilities (*such as themselves*) understand and respond to public photographic images of people so labelled) they are cognizant that their participation in the project hinges entirely on their possession of the label “intellectually disabled” – they *know* this. But at the project’s onset this identification, this knowledge, while perhaps not buried, seems to have been placed somewhere else, somewhere exterior to their first engagement with the images and to be something they are not really considering or perhaps even conscious of. I am surprised by this.

In part, my surprise links up with an insight they bring forward later in the project: the failure (refusal) of many of the images (photographers) to show more than the ‘outside’, more than the corporeality of the impaired body (Duffy, 2010): the inside – the person – is not revealed, not

exposed; it remains veiled and hidden from view and thus unknown. This observation seems important, not only for its content but because of my own observation that their first looks are similarly distant, similarly concealing. Sam, Bob, Donna and Robin begin their own looking from the outside: positioning themselves outside of the image's frame, to some degree outside of the category of 'people with disabilities', and (consequently? deliberately? unknowingly?) outside of themselves, outside of their own experiences as persons with intellectual disabilities.

Struggling to make sense of this, what becomes clear is that what is most immediate, most salient to them in these early meetings is having been called, *asked* to look *and* to speak to what they see. In calling them to stand before these public photographic images – as experts – to look, to judge and evaluate them, I have conferred upon them legitimacy, the '*entitlement*' to look, the right of inspection. The assignation of this status, their startling preoccupation with and exercising of such proves vital to their work, to their looking. The look they bestow upon the images at this phase (and, indeed, for the project's duration) is not a casual one – far more than a disinterested manner of looking (such as glancing, glimpsing, scanning or surveying (Garland Thomson, 2001)), it is concentrated, focused, determined, attentive but not easily characterized. I wonder if, given my emphasis on inspection, it is best described as a gaze but abandon this for, while invested with an element of authority, unlike other 'gazes' typically imposed upon visual representations of people with intellectual disabilities (i.e., the medical gaze or the ableist gaze) their look is not a pathologizing, objectifying one that manifests the differential power relationships between the different subject positions of 'looker' and 'looked-at' (Garland Thomson, 2001). It is a critical look to be sure, but dissimilar to the ableist gaze in that it exemplifies an ongoing process, a work-in-progress, as opposed to the classificatory gaze that seeks to permanently and irretrievably "fix" people by affixing to them the boundaries of a rigid

and static label. Further, and more significantly, it is different in that it derives from a non-hierarchical and, as-of-yet unacknowledged disabled space.

I come to realize that the group's early looking and responses reflect the complexity, and also the dangers and possibilities, of their positioning in this project: their positioning in relation to the people in the images; and their positions in relation to the act of inspection. Their initial lack of acknowledgment of their own positioning as people with intellectual disabilities means that theirs, at the outset, is a look from a distance, a look that, while acknowledging their physical proximity to the image and the subjects/objects of the image, their position in front of (yet separate from) the image (and from me), ignores their personal proximity to 'intellectual disability'. It unsettles me in that it regards (and demarcates) the people with intellectual disabilities within the images as unknown, as other, as separate – and thus outside of themselves.

While not initially responding as such, they *are*, however, part of the same group as the subjects/objects of the image and, consequently, subject to the same kinds of scrutiny and inspection (and objectification) as the people with intellectual disabilities in public photographic images; to the very same gaze that led to the very production of these images. The spatial relationship between spectator/viewer/observer and spectacle/viewed/observed is one that involves distance: perception takes place across difference (Garland Thomson, 2001:339-40). Bob, Donna, Sam and Robin cannot completely claim this distance or difference.

Garland Thomson's work on the rhetorics of photographic imaging of people with disabilities (2001) offers a language by which I can describe this doubled relationship to viewing/inspecting photographic images – and helps me better appreciate how the group members initially take up their positioning in this project. As *both* "seer" and "seen" (Garland Thomson, 2001:344) Robin,

Bob, Sam and Donna occupy a unique viewing space and position^{xx}.

Identification (by self and other) as ‘seer’ accepts/confers not only the right of inspection, but acknowledges the implicit necessity of the (recognized) ability to ‘see’. I refer here not to the ‘physical’ ability to do so (this would most certainly require another discussion, one not possible here) but to the assumption of competence, of visual literacy: the belief that one possesses the ability to read an image, to respond to and interpret that which they see. While the group members seem to recognize that I hold this belief about them, this is not an assumption typically made of people with intellectual disabilities by the larger non-disabled population and it is this that begins to clarify both their initial uncertainty and hesitancy to proffer an opinion and also the enthusiasm with which they quickly adopt the role of ‘seer’. It says to them something that is so rarely said: *you* can read the images and, further, *you* are uniquely able to read *these* images.

Identification as ‘seen’ follows an inverse pattern for, while the non-disabled viewer has a long and well-established history of regarding people with intellectual disabilities as ‘seen’, as objects for viewing, conceding their own status as ‘seen’ is, for Robin, Sam, Bob and Donna in the instance of this project, a wavering and layered process. Complicating (or perhaps simplifying?) the construct of ‘seen’, people with disabilities are never just (or truly) ‘seen’ by non-disabled others, but are each time ‘seen-as’. Conjoining vision with a determined knowing, ‘seeing’ people with disabilities is understood by many disability theorists and researchers (see, for example, Clare, 2001; Darke, 1998; Garland Thomson, 2001), and by the group members, to be very much controlled; with disability imagery the viewing audience is ‘blinker’ (Kratz, 2002:1). For Robin, Donna, Sam and Bob, being ‘seen’ – being inspected – is one thing; being ‘seen-as’ – as ‘intellectually disabled’, as like the people in the photographs – is quite another. The process is a wearing down and shoring up of their resistance to such an identification. An

awareness of themselves as ‘inspected’, and also as ‘like *them*’, proves a muddy, leaky, and painful positioning that assumes much greater significance as their engagement with the images progresses. It effects a change in how they look and in the experience of looking. The complexity of this process – a process of exposure and wounding – emerges as they become more and more familiar with the task at hand, move into and out of their work with different images, and place images in conversation with each other while moving into and across new spaces, new depths in their looking and experiencing of the images.

Wounding exposures: Looking from within.

In this project, the right of inspection comes with a cost. Consideration of the emotional register – Robin’s, Bob’s, Sam’s and Donna’s responses to the images at the level of memory, biography and self-identity – unveils this cost.

Let me start by muddying this assertion just a bit. For certain of the images (I am thinking, in particular, of three of the four *Benetton* images: the woman holding the boy, the boy wearing a hat, and the girl in the sweater) exposure to the images was experienced as a positive thing, one heartily welcomed by the group. Arguably short quotations (Berger & Mohr, 1982), these images do not immediately “prick” or “disturb” (Barthes, 1981:27); they are easy for the group members to talk about, easy to understand. These particular images are labelled “good” images – “we like these”. Imposing upon the images the role/function of biographical surrogate, they signal that which Sam, Robin, Donna and Bob want and value; what they desire to be and how they wish to be seen and treated. The group members find that they can (and, indeed, they choose to) identify easily with these images. Working with them, they physically draw them close, smile upon them; their mood is light and jovial. More significantly, they metaphorically move closer to the people with intellectual disabilities in the images, gravitating towards the

happiness and apparent lack of strife they see within. They are pulled towards the images by what Sam refers to as their “appearances” – the (in their minds) positive and respectful visual imaging of the subjects of the images – and by the “insider’s appearance” – the self-contentment that Sam and the others read on the faces of those in the images: this is as it should be. Garland Thomson (2001), writing from disability studies perspective, critiques the *Benetton* image of the child wearing the hat and, contrary to the group members, does not evaluate it as positively. She proffers the image, representing as it does the visual rhetoric of the sentimental, maintains a distancing and unequal power relationship between the looked-at child with a disability and the non-disabled viewer. It is possible that the group members’ responses to this image could be read as containing an element of the sentimental, yet they are not non-disabled viewers nor differently disabled viewers (as is Garland Thomson) and their responses simultaneously close the distance between the child as viewed and the group members as viewers. While insisting the image is a good one, Donna nonetheless points out that, sometimes, even such seemingly innocuous and pleasing images can hurt. With sadness, she describes how the *Benetton* image of the child with the hat makes her think about how she was treated by her family as a child and how she would have preferred to be treated in the manner she believes this child to be treated.

Other images (the majority of the images) Donna, Robin, Sam and Bob work with are more painful, less welcome. Mostly, theirs are difficult responses to what they regard as difficult images. The work necessitates looking at images that are uncomfortable, unsettling, troubling. It requires time spent with these (sometimes very) difficult images. It provokes personal engagement to a degree that wounds.

Barthes muses on the relationship between spectator and image, exploring photography as a wound: “I see, I feel, hence I notice, I observe, and I think” (1981:29). Viewing is not simply a

critical engagement with the image, it is also an *affective* relationship for the viewer with the image. At times, the relation can be one of comfort, which it seems most of the *Benetton* images are for the group members – this is what makes an image ‘good’. But, in distinct contrast to the group members’ position, Barthes suggests that a ‘good’ photograph is one which pricks and disturbs. Hirsch (1997) notes the priority that Barthes, in *Camera Lucida* (1981), appends to this affective relationship to viewing photographic images. While (like the group members) Hirsch is keenly aware of the socially constructed nature of photographic representations, she is nonetheless similarly drawn to consider viewing as an affective relationship, especially with more difficult, traumatic images. Attesting to the difficulty, the harshness, of their exposure to most of the images they work with, viewing the images arouses in the group members numerous other, more difficult, emotional responses: compassion, sadness, anger, confusion. The force of this exposure is matched by their outrage over how someone could take these pictures. There is an embodied and visceral response to these painful images, and they emerge from this exposure enraged and wounded.

Donna and the others were not able (did not even appear to try) to hide their confusion over what they saw in the images. Their discomfiture was writ large upon their faces and bodies, poignantly expressed in this embodied saying and through their words. Tears, anguished and raised voices, fists banging on tables, hands comforting each other, slumping in chairs or sitting bolt upright, physically exhausted or animated, distressed looks exchanged with each other and with me – their palpable despair over how people with intellectual disabilities could be so forsaken, so mis/taken, was heartrending. At times, the disjuncture between what they saw, what they read in the images, and their own experiences, desires, values was almost beyond comprehension. How could *David* be so un-cared for? How could a child (in *Blatt*) be treated so

heartlessly? Why wouldn't they tell us *Tracy's* story instead of telling us about the wheelchair? Undeniably hard for them to bear, it was, for me, similarly difficult to watch. Their distress returns me to Barthes' noeme of a photograph - "ça a été" (this has been) – to his unassailable belief in reference and a notion of 'truth' in the picture (1981:77). A photographic image of a person is understood to be more than a culturally constructed artifact; it is also a trace (Berger & Mohr, 1982). Donna, Bob, Sam and Robin are distraught as they come to the possibility that this mistreatment of persons with intellectual disabilities in the images has actually happened, that the real people in the images are/were so abused. Seen in and through these images, people with intellectual disabilities are never seen safely (Cixous, 2001:6). Understanding the images to be created by non-disabled others, they arrive at an unwanted explanation for what they see: non-disabled others don't care about people with intellectual disabilities. They don't want them and this not-wanting is tied directly to their having an intellectual disability. This is, thus, the said of the images. Exposed to these images, to this saying of the destructive triumphalist/ableist perspective, they run up against the full extent of the devaluation of people with intellectual disabilities.

Wounding exposures: Looking in.

Cixous talks of 'ascending down' towards "the thing that is both known and unknown, the most unknown and the best unknown" (1993:38). Ascending down necessitates an unburying, a moving toward and making visible that which one has chosen not to see. Possibly the most painful piece of this project for Donna, Sam, Bob and Robin is that they are exposed to and deeply wounded by that which they already know (but had buried, set aside or resisted), that which is, for them, unsayable: that in the eyes of the typical non-disabled viewer they were regarded as 'same' – as a being identical to the objectified and pathologized objects/subjects of

the images; not only ‘seen’ but also ‘seen-as’ and, in this way, ‘not-seen’, never really known. “Oh God, don’t let this be me!” (Donna) And more, that like the people with intellectual disabilities in the images, they, too, are unwanted. These visual representations put not only the disabled objects/subjects of the images ‘in their place’, but effectively position all people with intellectual disabilities, *including* themselves, in that same static, narrow and confining place. Seeing themselves through borrowed vision (Cixous, 2001), through the ableist lens, is brutally painful. Experiencing the images this personally, they hit too close to home. I am unable to forget Donna’s heartbreak over the lack of respect, of concern, of care shown to her by those members of her family who regard her primarily within the parameters of intellectual disability. Nor can I push from my mind, the hurt I saw on Sam’s and Donna’s faces when confronted by the security officers at the university. Looking-in proves painful and hard to do and, as a result, looking cannot always be sustained. Regulating their ‘seeing’ and ‘not-seeing’, at times they cannot look at the images and must close the book, push the photographs away, avert their eyes. At other times, they cannot look at each other. Sometimes it is impossible for them to look at me and they must turn away, avoid my eyes when self-disclosure becomes more than they can bear or wish to share. They move between making visible (looking-in) and in-visible (refusing to look, not-looking), exposing or hiding the thoughts and emotions connected to this self-inspection. The images then are, at times, overwhelmingly difficult to see: because of the treatment of people with intellectual disabilities that they read in the images, because of what they say/tell non-disabled viewers about people with intellectual disabilities, but also because of what they say/tell these viewers about *them*, about Donna, Bob, Sam and Robin, a telling they feel powerless to ignore or to overturn; a telling that hurts. Moving towards their own ‘best known unknown thing’, the group members are moved towards acknowledgement of the degree and types of ways that they, too, are constantly inspected – “people will be looking at you”,

“they’re gonna look at you for sure” – and the consequences of such. In taking up the right of inspection in this project, Bob, Donna, Sam and Robin wind up encountering more fully (or, in a different way) *how they themselves are seen*, and they also end up inspecting themselves.

In *Camera Lucida*, Barthes writes at length about his engagement with an image of his deceased mother (1981). Looking at this particular photograph of his mother “provokes [for Barthes] a moment of self-recognition which, in the reading process becomes a process of self-discovery, a discovery of a self-in-relation” (Hirsch, 1997:2). More than just a bifurcation of object and viewing subject, Sam, Bob, Donna and Robin are similarly touched by these painful images and their engagement evolves into a personally experienced one; a ‘discovery of a self-in-relation’ to the images, to other people with disabilities, the non-disabled world, and to themselves. The work evokes personal memories of shared or similar experiences to those viewed in the images, memories of their own experiences of oppression, marginalization, and violence. They connect the moments of the photographs (Baer, 2002:127) to their own moments. Moving into this emotional register, the work nudges them towards a looking-within, towards self-reflection and self-disclosure. The right of inspection thus comes to be understood to carry with it the need for self-inspection and their critique moves inward. This is, however, not so much a critique *of* the self (although at times it reveals negative feelings about the self), but a critique from a deeper place, one that is more admittedly, or at least consciously, within the self. Their looking shifts, coming to exist as a movement across and between the inside and outside spaces and the interplay between them. What transpires is a progressive blurring of the image with the subject of the image and with themselves – a conflation of image, object/subject of image, themselves as ‘seer’, ‘seen’ and ‘seen-as’ (as being the same as the intellectually disabled subject/object of image). There is slippage between the particular of their own lives (their experiences and sense-

of-self), their perception of the lives of the people with intellectual disabilities in the images, and the universal experience and understandings of people with intellectual disabilities that they read in the images.

For some, a deep ascent was not required. Donna, in particular, seems to hold this knowledge just below the surface and the quickness with which her readings of the images find their roots in personal experience testifies to such. But while she appears the least resistant to acknowledging being seen and seen-as, she is not at ease with it: this knowledge remains extremely uncomfortable. While much less obvious and more quietly articulated, to my eye it feels as if Bob shares this barely buried identification. In contrast, Sam and Robin must dig further and they push against this unburying more actively and for far longer than either Bob or Donna.

This resistance, this struggle to ‘not-see’ how many non-disabled others see them, unveils the tension (articulated most clearly in the chapter, “Oh God, don’t let this be me”) between cognition and affect, critique and desire. It moves between a critical understanding of how their disabilities are socially constructed, the meanings of intellectual disability imposed upon them in and through visual inscriptions, and how, despite this awareness, they still, to a great degree, desire to be ‘normal’. They wrestle with the desire to accept oneself *as* oneself (when confronted daily with a non-disabled world that, for the most part, refuses to accept them) and the opposing desire to be ‘normal’ (or at least to ‘pass’, to be perceived as more ‘like’ than ‘unlike’ non-disabled others). Citing the power of the cultural story of “normalcy” to “structure our shapes”, to govern our bodies and behaviours (Garland Thomson, 2007:113) and how we are seen, Robin, Bob, Sam and Donna simultaneously highlight its cost. In trying to ‘pass’, they work (with varying degrees of success) to mute their difference (Garland Thomson, 2009), to create a veil that will hide their disability from the public gaze. Robin’s refusal to be photographed, to be

‘caught’ on videotape, is the most extreme version of this. It is very important to Robin to hide his disability (which he acknowledges), but also to actively resist this lens, this being ‘seen-as’. Of all the group members, Robin has the least faith that any new viewer or photographer (even the other group members) will effectively change this lens. At the same time, the counterstory that has been created, the possibility of being the ‘seer’ and the possibility of being seen differently, seems the source for the decision made by Donna, Sam and Bob to resist the cultural story of normalcy, to, instead, expose themselves to the risk of identification as ‘same’ by taking and using photographs of themselves in the project. Pointing to the pedagogical potential of images, of showing and of telling in conversation with non-disabled others, they seem to highlight the risk of hiding (their disability) behind a veil: remaining unknown or known only as the ableist ‘victor’ would dictate. Speaking to one’s right to hospitality, Derrida (2001a) similarly notes the necessity of being seen and heard. Without such seeing and speaking, one remains a victim, remains within a darkness and a silence from which it is very difficult to escape.

It is the spectacle and visuality of the images that most strongly unhinges their comfort with identification of the self (and the Others in the images) as ‘disabled’ because, in the images they look at, people with intellectual disabilities are singled out as a “dramatic case of not belonging” (Davis, 2002:105). If all of the images they selected were similar to the three *Benetton* images that they liked, this project and their own exposure and wounding would not have unfolded as it did. But in these more difficult images they can readily see how the staging of photographs results in people with intellectual disabilities being constructed as incommensurable, too far beyond the limits of the conceptualization of ‘same’, of ‘normal’, even of ‘human’, to allow for an empathetic identification on the part of a non-disabled viewer or for a ‘safe’ or meaningful

identification on the part of the group members. They understand that self-identification as ‘same’ in this context, given the spectacularized constructions of intellectual disability they see in the images, would be a false one for, as they state many times, they know no-one who looks like *that*. At the same time, they experience an inner struggle to be comfortable with, if not proud of, who they are and to be equally comfortable with membership in this particular group – people with intellectual disabilities. This is another aspect of the violence of these images – they make identification with the people in the images impossible, or at least something to be resisted. In either case, it is painful. In this instance, this translates to their inability, their difficulty, their ambivalence towards acceptance and valuation of their own and Others’ differences. The group members try to achieve ‘normalcy’ on some level by distancing themselves from the people with intellectual disabilities that they see in the images. Identification as being the ‘same’ as the people in the images is resisted – “they are different, more disabled, than me if they are in the paper”. While Levinas suggests that identification with the Other is not/should not be necessary for a valuation of difference (is, in fact, impossible) (transl. Lingis, 1969), a number of disability theorists assert that there has to be, at the very least, identification of people with intellectual disabilities as a ‘fellow human’: without this, violence against this Other is more easily inflicted, less actively (and effectively) opposed (Bogdan & Taylor, 1989; Byrne, 2000; Linneman, 2001; Sobsey, 1994).

Cixous writes: “Perhaps going in the direction of what we call truth is, at least, to “unlie”, not to lie. Our lives are buildings made up of lies. We have to lie to live” (1993:36). In the context of this project, the group members’ way of tolerating what they see, making more tolerable their lives in a visually mediated world is, at first, to ‘lie’ in order to resist what they know (and what, it must be acknowledged, in limited circumstances, they are ready to admit), and what they know

I know – their identification as a person with an intellectually disability – because it is often too painful to admit to being viewed as ‘same’. But I wish to stress that this is what I saw in the space of *this* project and I worry that it might mis-represent Donna, Sam, Bob and Robin, failing as it does to speak more fully to their feelings and activities outside this space. Similarly, it masks the fluidity, the contingency of their resistance/acceptance of self-identification as intellectually disabled even within this project – a fluidity I hope was more evident in the preceding chapters. That being said, it would appear that the taking up of the right of inspection necessitated an immediate and prolonged exposure to and confrontation with these issues, with the questions of self-identification and identification by non-disabled others as ‘same’ that, while undeniably painful and frequently resisted, was significant to the work, and to the process of the doing the work, and that did carry certain gifts, and possibilities which I will turn to in an upcoming chapter.

Let me call again upon Cixous (1993), this time making reference to her supposition that being wounded is a prerequisite to thinking, to disrupting that which we think we know. She writes that the text, or scene, forms a door, a window, an opening which we either enter or don’t enter. She admits there is risk involved in opening oneself up to this encounter, in answering this call, as one’s preconceptions and prejudices may be tested. The tests may wound, may strike us like terrible events “that do and don’t do us good, that don’t do us good in doing us good” (p.17). But, she concludes, it is necessary to have been wounded in order to ‘see’ and to tolerate the ‘seeing’, to understand (Cixous, 1993). I would proffer these ideas have merit in reflecting on the processes of exposure, wounding, and thinking that Donna, Bob, Sam and Robin underwent in their journey, in their exercising of the right of inspection. But, I wonder about the adequacy of Cixous’ theory when considered from the lens of the ethics of this type of work. Cixous is

writing about writing, about the process of unburying necessary to 'good' writing. In fairness, she is not writing about marginalized and oppressed people with intellectual disabilities looking at oppressive images of other people with intellectual disabilities: does this theory hold if you start from the space of already being deeply wounded and then looking at deeply wounding texts? Is such wounding necessary to effect change?

Chapter 14 – The Responsibility of Inspection

Introduction

Taking up the matter of the right of inspection over public photographic images of people with intellectual disabilities, the previous chapter unavoidably touched upon the notion of a responsibility. Disrupting the triumphalist perspective; viewing public photographic images with a critical yet compassionate eye; and demonstrating awareness of one's own positioning in the viewer/viewed relationship are each exercises in responsibility. In this chapter I extend the discussion of responsibility, by considering two inter-related questions, evoked for me by and through the group members' work and intended to broaden my/their previous reflections on what happens when people with intellectual disabilities take up the right of inspection:

(How) do viewers with intellectual disabilities understand themselves to be faced-by the Other with an intellectual disability in the image, and in what respect are they (or do they believe themselves to be) responsible when so faced?

My wish then is to more fully reflect upon the links between the right of inspection and the question of responsibility that ensues. When a viewer with an intellectual disability – Bob, Donna, Sam and Robin – encounters the Other with an intellectual disability in a public photographic image, what is it that calls them to respond, to take up this right of inspection responsibly? At issue is not so much the (refusable) assigning of a responsibility from the outside of this seer/seen relation (effected by my call to them to look, to take up the right of inspection). Rather, emphasis is placed upon how, when face-to-face with, and feeling faced-by, the dis-abled Other in the image, the group members' assume (a call for) responsibility; a responsibility they feel less able – if not, indeed, unable – to refuse.

Levinas' work on our ethical responsibility to the Other thus frames this discussion. The origins of both the understanding they have been addressed, and their decisions around the answering of this address, are, I think, located (as Levinas suggests) in their very particular subjective viewing position, which was laid out in the preceding chapter – their facing (and being faced-by) from within the interiority of their own (self)identification and experience as persons with intellectual disabilities. There is a reflexive engagement with, and active (however difficult) assumption (and sometimes refusal) of, an ethical responsibility for the persons with intellectual disabilities in the images.

To begin this chapter, I rely once more upon Baer's (2002) work with Benjamin's thesis on disrupting the triumphalist gaze. I am drawn now to his insistent articulation of how recognition of the 'beyond' of the photograph (in Barthes' use of the term) is a necessary condition for this disruption to occur (2002). Barthes writes of the anterior future of the photographic image, the promise of a future extending beyond the historical moment of the photograph (1981). Baer takes this idea and proffers that "when confronted with photographs meant to deny the humanity of their subjects, we need to acknowledge that something resides "beyond" the photographic gaze" (2002:144). He contends this is the requisite response to being faced by images that objectify and dehumanize the Other, images taken by those who are overwhelmingly dominant over those they photograph – to search for something more, to see beyond that which the image permits us to see. As regards the Genewein images of Jews in the Lodsz ghetto, Baer maintains the viewer's seeing must register more than a singular preoccupation with the death of the photographed Jews. It is this which can disrupt the Nazi photographer's schemes, this which will upset attempts to control and determine that which is and is not seen. Herein lies for Baer, the ethical dimension of looking at images of violence. It is, I would further argue, for the group

members the responsibility that adheres to the right of inspection, this searching for, and finding, a ‘humanizing’ beyond. As such, it sets the stage for the consideration of questions of address, response, and responsibility/response-ability that closes this chapter.

The Human(izing) Beyond

As I trust has been made plain in the preceding chapters, the group members struggle with the (un)believableness of what they see in the images: that people with intellectual disabilities could be so forsaken. Re-contextualizing this in the language of enacting responsibility through the search for a humanizing beyond, I remind the reader of their immediate and almost unanimous recognition of the dehumanization and objectification, the constructed dysfunction, of people with intellectual disabilities found in the examples of photographic representation they chose to work with (only a very small number of images are exempted from this categorization). Robin, Bob, Donna and Sam point to how people with intellectual disabilities are visually imaged and imagined as (at best) empty subjectivities, defined by overarching totalizing discourses of disability as undesirable, tragedy, lack. Their critique directs me to incorporate into a discussion of ethical responsibility and the beyond of a visual image, Butler’s (J., 2004) questioning of what faces are and are not admitted into the public visual domain and, important for this discussion, the terms and consequences of these admittances. Informed by a Levinasian concern with the face of the Other, in this essay Butler (like Baer (2002), Derrida (1998), and Kratz (2002)), attends to presence and absence, to ways of seeing, and the im/possibility of knowing.

Extending this to the questions posed in this chapter, what the group members clearly grasp is, as Butler describes, the ways in which the media, through its control over access to and practices of visual representation, evacuate the human through the image by adhering to/determining normative schemes of intelligibility that “establish what will and will not be human, what will be

a livable life, what will be a grievable death” (J., 2004:146). As Bérubé (1996:85-6) writes: “(h)umanity depends on social recognition, as do all other forms of meaning. Only humans can decide the meaning of a thing, including a word like “human””.

The unassimilability and undeniability of what they see effectively splinters the group members’ own (tenuous) perspectives, their own (preferred) points of view. Provoked is a “Barthesian shudder”: photographs taken of sites of traumatising and destruction cause the viewer to “shudder over a catastrophe that has already occurred” (Baer, 2002:145). When looking at images of the Lodz ghetto, this shudder is evoked by the viewers’ knowledge that the Jewish people in the images were all murdered (Baer, 2002). In the space of this project, the group members ‘shudder’ over a catastrophe that, in their estimation, continues to occur. While neither disavowing nor minimizing the awfulness of what they see, their shudder incontrovertibly stems from more than the representation of atrocities perpetuated against people with intellectual disabilities which they perceive taking place in and through the images (for example, incarceration, infantilization, neglect, etc.). It derives, too, from their understandings of the reasons *why* these atrocities occur – the evacuation of the human – the devaluation and dehumanization of persons with intellectual disabilities (and, as consequence, of themselves). This recognition appears to trigger their desire, their need to see – or, perhaps, the inevitability of their seeing – a human(izing) beyond in the images they work with.

At first blush, this might provoke a sense of familiarity, and readily do I cede this observation. This need to see more has been addressed in the previous chapter, but in a manner presaging its use here. In that chapter I wrote of how the group members are visibly upset with the original images on a number of different levels but, importantly, they are upset because they comprehend these depictions of intellectual disability as un-truths; as perceptions and constructions born of

the ableist perspective. From their emic and embodied position *as* people with intellectual disabilities they know that bodies and lives (their own and those of the images' subjects) are not as reductively limited as is portrayed in the images: there is far more to it than what non-disabled viewers and they themselves are given-to-be-seen. But I wish to re-visit this idea here, en-fleshing it further by attending to this corporeal emphasis on human bodies and human lives, attending to their function and bearing in the group members' articulation of a human(izing) beyond, to their more explicit engagement with the question of their ethical responsibility to this Other in the image.

It would seem unassailable at this point that what Donna and others 'see' when they look at each of these public photographic images is not simply a constructed and depersonalized 'object'. They see beyond the photograph, beyond the photographer's gaze to a 'real' person and a 'precarious' life – to “the precariousness of life itself” (Butler, J., 2004:134) – and thus to the precariousness of our ways of knowing and claims to know (Chambon, 1999). When looking at images *they like*, they can point to, what are for them, markers of the human visible in the image. The hands of the woman holding the girl in the *Tracy* image; and the loving gaze the woman directs towards the child in the *Benetton* image, for example. Bob points to the background of the *Arbus* image and his articulation of the trees and sky, the 'living' environment, similarly attests to living subjects. These signs carry, for them, an evidentiary weight, a 'proof' of a human(izing) beyond. Rupturing the “funereal immobility” of the image (Baer, 2002:140), the group members view movement, possibilities, signs of life, signs of living – signs that are, however, likely unintended by the non-disabled photographer, likely discounted or differently read by the non-disabled viewer who can see only the absence of the 'normal human', only the photographer's gaze. Awake to the precariousness of the Other (Butler, J., 2004), they note in

the images *they dislike* the flatness of the image (Barthes, 1981), and point to the absence of visible signs of the human and of humanity, yet see beyond this de-humanizing representation to the ‘real’ person who, for them, haunts the images.

Searching the photographic ruins, their work, influenced as it is by their own positioning as seer and seen, continually comes back to the relation between the image and a life – that of the person in the image, or their own. I think of the way the group members flip back and forth through the images (the originals and their own), putting them in conversation with each other. Engaging, too, in conversation with each other about the images, they similarly speak ‘to’ the images, and ‘to’ the ‘real’ people in the images: giving voice to that which they would say to the subjects were they ever to encounter them in person. They express often this desire to meet them, to hug them or shake their hand, and to talk with them in order to find out the ‘truth’ about them (and to learn how they feel about having been photographed in this way). Similarly, many requests are made of me to provide (or to find, when my own unknowing is revealed) information about these photographed people with intellectual disabilities. All of these observations, I would argue, attest to their recognition of and confidence in the possibility, the existence of the human(izing) beyond.

It is in their storying of the original images (taking place prior to their transforming of the images) that I think they most successfully (but not unproblematically) point to this human(izing) beyond. Derrida (1998) proffers that we all have an intense desire for stories, an overwhelming need to story that which we see, to ‘arrange’ the image as a means of making sense of it. We work to fit that which is new and unfamiliar into that which we already know (Garland Thomson, 2009). Struggling so completely with what they see in the bulk of the images they work with, unable to let go of the (for them, very real) referent, the group members

similarly struggle to story the images, to find a way to explain, to understand, to make sense of what they regard there; for a way to ease the wounding. This attempt at storying is, in part, rooted in their deep worry for the lived consequences of images such as these: teasing, isolation, rejection, harm. It is also an outright refusal of these imaged 'lives', of these (un-truthful) frozen moments intended to stand in for the whole of a life (Bal, 2004). In their place, the group members imagine (often very detailed) lives for the people with intellectual disabilities within the images – a past, a present, and a future beyond the dubious 'present' of the image. As articulated by Berger and Mohr, "An instant photographed"..."can only acquire meaning insofar as the viewer can read into it a duration extending beyond itself. When, as a viewer, we find a photograph meaningful, it is because we are lending it a past and a future" (1995:89). In their struggle to make sense of the images, they move the Other outside the static, atemporal and singularly reductive biological story of the 'defective body' told by the image. Instead, their storying unveils a biographical life, one which compellingly distinguishes between 'being alive' and 'having a life' (Fudge Schormans, 2005). This storying enacts their responsibility for the persons with intellectual disabilities facing them in a different way than their previous forms of responsibility-taking.

Let me offer up their early discussions of one image to help make this point. Confused by the hostile staging of the girl's body in the original *Tracy* image, reluctant to submit to its message of de-valuation, the group members substitute other imaginings. For example, Bob thinks of the girl as having just returned home from a very busy (but very good) day "travelling around" and, while happy, she is also exhausted and wants to get out of her wheelchair, to relax. Bob offers details as to how she may have spent her day. He tells how (he felt) she felt about it. He fleshes out a positive relationship between the girl and the woman holding her.

A second storying explains it somewhat differently. According to Sam, the girl's body, her hip, is "hurting her", she needs "a break" from her wheelchair and to be held and comforted by someone who cares for her. In pain, she seeks out the care and affection of another, and feels better as a result. Although Sam's story attends quite specifically to the girl's body, to her biology, his emphasis is on love, on the reciprocity of the relationship between the girl and the woman holding her: in a sense, an easing of biological pain by biographical care. Sam's story corresponds to a growing number of literary and research accounts that narrate biographical lives and confound attempts to restrict the understanding of 'intellectual disability' to a biological (and problematic) entity (Fudge Schormans, 2005). Schaefer's memoir of her relationship with her severely disabled daughter (1999); Bogdan and Taylor's writings on the possibility and value of humanizing relationships with people with more severe intellectual disabilities (1989); and Linneman's work, in which he writes of the process whereby "(s)omething happened, and I turned retards into people" (2001:2), immediately come to mind. Like the stories Bob, Sam, and the others tell, these works endow their subjects with intellectual disabilities with an interior life; figuring them as thinking agents; self-directed; capable of choice, preference, and self-expression. In this way, their work establishes and marks these disabled lives *as* lives – livable lives – and as lives lived and felt (Butler, J., 2004) – the other of the original images. It troubles the dehumanization and objectification in the images that would lead non-disabled viewers to the conclusion that these disabled bodies are without history or have only a very limited or arrested one (Fudge Schormans & Chambon, 2010), and challenges that which can, and cannot appear in the public sphere. What is also important is that this attempt to locate and articulate the 'human' took place very early in their engagement with the original images.

Embedded in their storying of the images, are the group members' attempts to extricate the

disabled subjects of the images from the frame/framing, to pull them free of the image in order to ‘see’ the real person, to really ‘see’ and then to ‘tell’ the real story. What they search for, see, and tell is the lived life they believe to exceed beyond that which they are faced with in the image. Such a narrative imagination is argued to have value in that it assists the viewer to see beyond the immediately visible (Smith & Pérez-Samaniego, 2009). And, as I noted earlier, Baer (2002) says it is this recognition of the photograph’s capacity to launch the viewer’s desire to see a Barthesian beyond that permits the break with the triumphalist/ableist gaze. The group’s efforts here might, I grant, be understood as mere story-telling, the ‘making-up’ of a story and a life and, thus, the ‘making-up’ of a person. From a Levinasian frame that posits the impossibility of ever truly knowing the Other or being able to speak for this Other (1969), one’s ability to story or narrativize the life of an Other is quickly called into question (Smith & Pérez-Samaniego, 2009). The tendency in either of these cases might then be to simply dismiss it. From a constructivist lens, this ‘people-making’ (Hacking, 1999) might be differently valued. For example, theorists arguing for an understanding of ‘disability’ as a construction, typically also speak to the possibility and necessity of its re-construction; for example, as valued versus de-valued difference (Darke, 1998; Hall, 2007; Hevey, 1997; Jeffreys, 2002; Kittay, 2002). And, undoubtedly, what Sam, Bob, Robin and Donna do could be described as a re-constructive project: a means of making-human – making-*a*-human – s/he who was de-humanized. Returning for a moment to Garland Thomson, shape no long structures story – story now structures shape (2007). But it strikes me as less a re-construction (or, as Derrida (1998) might suggest, a re-invention of the invented ‘other’) than a claiming (even exclaiming) of something they believe to have always been true, even if erased from view. Less a claim to ‘know’ the Other, than recognition and defence of something they understand to be fragile, at risk, but true and held dear: the humanness and humanity of *all* persons with intellectual disabilities.

Response and Responsibility: The Question of Address

Butler's essay, taking up the ways in which the media limits representation, addresses the exceptional: images the viewer was not intended to see. These images trouble the visual field by showing "a reality that disrupted the hegemonic field of representation itself" (J., 2004:151). She cites as an example publicized pictures of children burning and dying from napalm in the Vietnam War. The images are disruptive in that they "pointed somewhere else, beyond themselves, to a life and to a precariousness that they could not show" (p.150) and which the viewer, until the time of their publication, had not been allowed to see. Like Baer, Butler here is concerned with images of violence, of oppression, and her thesis shares a certain affinity with Baer's calling for a reading of images in which we see more than we are intended to see. And while Butler, in this instance, is referencing photographic images the viewer was *not* intended to see, whereas Baer concerns himself with images intended to be seen but seen in a very particular normalized way, both regard as important this Barthesian notion of seeing beyond; the necessity of the viewer's striving to see more than is immediately visible in the picture's frame, more than the limits of media representation will let us know (Butler, J., 2004), more than the triumphalist/determinative gaze wishes the viewer to see (Baer, 2002). Both argue for the imperative of seeing the lives beyond the image, the lives that "appear in their precariousness and their destruction" (Butler, J., 2004:150), and the lives beyond the destruction that, simultaneously, do not forget the destruction (Baer, 2002): lives that return us to the human, to the Other. Butler says this is necessary for an "ethical outrage that is, distinctively, for an Other, in the name of an Other". Without this we will not hear the call of the Other, we will be "turned away from the face" (J., 2004:150).

It is this notion of the call of the Other that I take up here: the call for response and

responsibility. The group members' restoration or (re)claiming the evacuated human, is a response to their unarticulated (and unarticulateable (Levinas, transl. Smith & Harshav, 1998)) understanding that they, individually (and, in the space of this project, in a way also collectively), have been addressed by each of the persons with intellectual disabilities in each of the difficult public photographic images they worked with. Their response to the Other reveals this sense of feeling addressed, of feeling faced by the Other, in the Levinasian sense – the face of the Other that is the trace of our already being in an ethical relation with the Other (Perpich, 2008). The proximity to the Other thus confers a responsibility.

This seems clear in that an 'address' seems not to be implicit nor inherent in their encounter with all of the images. The images they regarded as less problematic (for example, the two *Benetton* images of children – one wearing a hat, the other a sweater) evoke a different kind of response than do the more troublesome images they worked with. With these images, their responsibility is directed not by the face of the Other encountered in the image, but by concern for the self (i.e., the images provoking in them a longing for appropriation of these lives as their own – again, the image as biographical surrogate) or for the Other in another image. I think here of their contrasting the care they see in these two *Benetton* images with the un-care they read in the *David* and *Tracy* images.

The group members' responses to these encounters with the Other in the difficult images are both different and more than an answering of my invitation to take up the right of responsibility for this invitation was just that – an invitation – and thus refusable. Let me turn to Baer and to Garland Thomson to elaborate this point. Embedded in Baer's (2002) conceptualization of viewing images of violence is the explicit extending to the viewer of a call for, if not indeed expectation of, a 'response' and thus of 'responsibility'. In a much different tenor, Garland

Thomson, addressing non-disabled viewing of photographic images of the disabled, writes that *nothing* is expected of the viewer: the spectator to a photographic image is absolved of any responsibility to the dis-abled and disabled object of that image (2001). From the start of this project, however, it is clear that Bob, Sam, Donna and Robin do not understand themselves to be so absolved – they must respond, they are responsible. Not responding, not assuming some responsibility for the Other in the image, is not an option they can (comfortably) live with. Levinas writes that one's proximity to the Other dictates a non-indifference to this Other who, in facing me, concerns me, addresses me, and demands my attention (transl. Smith & Harshav, 1998). In their encounter with the Other in the images, the group members sense that they have been faced and addressed by the persons with intellectual disabilities they see in (the beyond of) the images. It is (in part) in this identifying and asserting the 'human' who resides beyond the images' borders, that they respond to this call that is the saying of their responsibility. It is in responding to the call, to the face of the Other, that this humanization occurs.

I mean not to imply on the group members' part a conscious, literal, or spoken interpretation that the persons with intellectual disabilities in the images are somehow 'speaking' to them; asking or demanding that Bob, Sam, Robin and Donna 'do something'. Their response to each image is not as an explicit or prescriptive call to action. Neither the call of the Other, nor the saying of their responsibility for-the-Other is (at least at first) a conscious one (Levinas, transl. Lingis, 1991). But the notion that they do, on a different level, feel 'spoken to', and that this 'speaking' invokes a responsibility, is apparent. As they work with the images, the group members talk a great deal about the persons with intellectual disabilities in the images: about what these persons might say to non-disabled others, how they might feel, what they would prefer. Reflected in their wondering about how the subjects of the image would react to and understand these images

and imaginings, is this sense of being called. Yet the group members never articulate that the person in the image, by any means, is asking them to do something. That a responsibility has been assumed (assumed inherent in their face-to-face encounter with particular subjects of particular images, and assumed – taken up – by them) becomes more evident as the project progresses. And, over time, they begin in a certain way to speak this call to responsibility through the transformations and the voicing of their concerns over their ability to fulfill it (a point I will address shortly).

The immediacy of the group members' response, the speed and intensity with which they articulate and grapple with the dilemmas and tensions they read in the images and their numerous responses (spoken, un-spoken; critical and affective; the creation of visual re-imaginings and imaginings), reveals to me their susceptibility to the address of the Other. Having accepted my invitation to take up the right of inspection, they could not/did not know, could not/did not anticipate what this might evoke for them. In this way, this susceptibility is an unwilled, unchosen susceptibility: "(i)t comes to me from elsewhere, unbidden, unexpected, and unplanned (Butler, J., 2004:130). And, as Butler writes elsewhere, it is the very condition of both their responsiveness to the Other, and their responsibility for the Other (2005).

Levinas writes that my proximity to the Other who stands before me, who "faces" me, dictates my responsibility to a "non-indifference" with regard to this Other who, before all reflection, concerns me, addresses me, and demands my attention (transl. Smith & Harshav, 1998). This is not an obligation that the group members take lightly. Nor is it one they feel able to defer to another. In the here-and-now of the encounter with the Other in the image, theirs is a here-I-am response: they are the ones who must respond (Diprose, 2001). At no point am I asked to do so and, while this might be explained by the structure of the project, by our differing positions in it,

it may not be this easy. Sam, Bob, Donna and Robin all comment frequently on my own particular kind of embeddedness in ‘intellectual disability’. They know this to be different from their relationship to intellectual disability but also to be quite different from that of many non-disabled others, and often they tell me they believe that I, unlike those non-disabled others, ‘understand’. They quite frequently seek out my thoughts and opinions on other matters, yet I am not understood to have any responsibility for the Other in the images. So, while I do not believe myself to have either the right or responsibility to determine the response in this context, I am somewhat surprised that the group members have so completely assumed this responsibility. I wonder further if their involvement in the self-advocacy movement is at all implicated here. Is this a factor in their assumption of responsibility. And, would they understand this responsibility to be one that must be/would be taken up by other or all self-advocates? Here, responsibility is understood to be theirs and theirs alone, and their work with the images is conducted with the utmost care and respect for the subjects of the images. *They* want to do a ‘good job’, *they* want to make things different and, thus, make a difference.

Let me here pull into this discussion Roger Simon’s engagement with this aspect of Levinas’ work in the context of practices of historical remembrance. Attending to the problematic of the inter-human, to problems of answerability and address, Simon is concerned with how one opens oneself to an Other and enacts one’s non-indifference; with how one attends to the experience of an Other. Let me return here to something I introduced in the theoretical chapter of this work, Simon’s articulation of a responsibility to the Other that provokes and embodies a “summoned *kavannah*”. *Kavannah* is a term in the Jewish faith typically referencing the attentiveness, attunement, and intentionality with which one engages in prayer. For Levinas, prayer is not only the relation between human beings and the divine, it is “a question of attention, wakefulness, an

orientation, a turning, and ultimately an adherence and responsibility” (Simon, 2003:6). This is understood by Levinas to be a form of presencing, a being-for-an-Other, that is, in essence, a "*sensibility*" (Simon, 2003:9). Sensibility is understood by Levinas as a vigilance in one's orientation to the said and to the saying of testimony, and, also, to how one is attending. It is therefore a doubled moment of attentiveness – informational and reflexive (Simon, 2003).

Attentive to the address of the Other in the image, as the project progresses the group members become more aware of how they are attending, how this attentiveness is enacted. The extent of their engagement with the *David* image, the multiple and incredibly thoughtful ways that they transform the images and their conversations around these, is an example. Raising questions, articulating tensions, struggling with what they see, they simultaneously engage in discussions as to how best to respond, how to demonstrate in their transformations that which they think is demanded: care, respect, love, belonging. They are concerned not to do harm. Certainly, I can see different levels of engagement, of awareness and concern, reflected in the different images they worked with (again, the *Benetton* images come to mind). If I consider only the response of transforming the images, the decision made as to how to transform them, then at times it does feel as if their response is understood to be so obvious as not to warrant a great deal of thought (and, here, Bob's decision to cover the man in the *David* image is an example). But this observation belies the reflexivity incorporated into their critique of the image, their attentiveness to their own attending taking place throughout the work with each image that culminated in each transformation decision. Again, theirs was incredibly care-full work.

Response-ability

To do such care-full work however can be extremely difficult. Let me close this chapter with my own attentiveness to this aspect of the group members' experience and consider responsibility in

the context of an understanding of response-ability.

Speaking to a concern congruent with Levinasian philosophy and disability studies, Simon (2000:9) asks, “who can bear the demand that we listen” to the persistent and traumatized voices of others, that we take their difficult memories into our lives and “live as though the lives of others matter”? What is one supposed to do with these stories that are the memories of others? Similarly, Baer (2002:145) submits that when people look at traumatic images, when they shudder over what has already occurred, this shudder threatens to become a “paroxysm of helplessness”, jeopardizing their ability to shatter the triumphalist perspective. Both Simon and Baer point to the inherent difficulty in responding to the precarious life of the Other who has experienced violence. To hear these stories, to look at these images, is undeniably painful. To then assume responsibility is a daunting and formidable undertaking. For the group members, what they see in the public photographic images is, as has been made plain, often much more than they believe themselves capable of carrying. On an emotional level, this seeing really hurts. Cognitively, it inflicts upon them more than they can manage: the question “How this could/can happen?” is, in many ways, far beyond their comprehension. Simon writes that being attentive and responsive to the Other invokes a vulnerability within which “knowing, being's disclosure to itself, marks a break with the thematizable, with the abstractions within which one grasps an understanding of who it is that addresses you and what might be the substance and import of his or her message” (Simon, 2003:10). One is exposed to a wounding that obligates one to respond and to be accountable even as one’s accountability is challenged. As has been noted in the preceding chapters, working with the public photographic images the group members’ are exposed, wounded; their own knowing frequently troubled, disrupted. At times, this has been almost more than they can bear.

For Donna, Sam, Robin, and Bob, the question of responsibility is very much complicated by the question of response-ability. They have entered this project from the space of already having been deeply wounded. The work itself has taken them, as Simon, Cixous, Butler, and Baer all write, to another place of wounding – a wounding necessary to effect change. Can they sustain more? Donna most poignantly articulates the conundrum that each of the group members speaks to at some point in the project: the impossibility of response – she wants to help but she can't. In part, this is because they are not always certain of just what is expected of them, of how to interpret the unspoken demand of the Other they see (Stocker, 2001). Fairly quickly, however, the structure of the project, the invitation to respond photographically, affords a way out of this dilemma. But, what is most evident is the challenge the group members face in managing their own (oft times very difficult) lives, dealing with their own experiences of marginalization, of oppression – experiences both different and, in many respects, astonishingly similar to those of the Other in the images that Bob, Sam, Donna, and Robin read in the images. To take up responsibility for another is to extend already over-extended resources for the barriers experienced by Sam, Robin, Bob, and Donna are (as for many people with intellectual disabilities) so extensive in number and kind as to often be overwhelming. Already exhausted by these daily battles, Donna, in particular (but not only) becomes quite anxious at the thought of having to deal with even more. As members of the same oppressed group as the Others in the images, their ability to assume responsibility may thus be compromised or confounded. It might appear to be more than they are capable of managing. Donna's exhortations, for example, arguably confirm such an interpretation. It is clear that while, as I have written, they understand themselves to be obligated to a response, to the assumption of responsibility, at times they strongly push against and even (at least temporarily) resist this injunction: they *cannot* be responsible for another, they *cannot* be held responsible, they *cannot* be blamed. And, in these

moments, it appears, too, that in some way they regard the demanding address of the Other as also entailing an accusation. Thinking once again about Donna, and about Sam, about the nature and the excess of their despair over their perceptions of an expectation they do something – about their equally strong insistence that they cannot – it appears to me as if they believe they are not merely being held accountable by the face of the Other but being blamed (or at risk of being blamed) by the non-disabled other (and the Other in the image?) for what may happen if they do *or do not* respond. In fact, there are moments when they state this quite clearly and powerfully. In such an untenable position, how can one respond? But what is very clearly revealed in the space of this project is that they do manage, they do respond, they do assume and enact a responsibility. Countering ‘evidence’ of their inability, they quite ably (if not easily) respond responsibly through their critique and their transformations. And, whether they accept or push against this facing by the Other, theirs is never an indifferent response, never an example of disinterestedness.

Chapter 15 – Corroding “The Comforts of Common Memory”

Introduction

Coming to see is irreversible and once we have seen something we can never not see it again (Cixous, 2001:11).

But there’s this. You see, we just can’t settle down after knowing, but we got to act. And some of us go nuts. There’s too much to do and you don’t know where to start. It makes you crazy (McCullers, C., 2000:155).

In their work with the images, what the group members come to see is their own mis-taking: the staging of frightening difference, helplessness and inability; the construction of people with intellectual disabilities as lesser, and of less consequence. What they also see dangerously inscribed in the images is their exclusion from the position of ‘seer’ and their restrictive and reductive positioning as ‘seen’ and ‘seen-as’: their invention as ‘other’. All four of the group members are exceedingly troubled by this. The depth of their wounding is such that, up to this point, it might be possible to deem their distress as being so deep as to overwhelm, to render them powerless, passive, silent (Martin & Spence, 2003). At the same time, they understand themselves to have been addressed by the persons with intellectual disabilities in the images, an address that demands a response. While oft times doubting their own response-ability, they further understand that they have to act.

Looking from their own I/eye, what Sam and the others do is very much a critical and embodied engagement with a piece of the visual record of intellectual disability: one that reflects not only their thoughts and feelings about visual constructions but also their position in the world. In addition to the verbal reporting, this project carves out space for the group members to also

express their response (to the image, to the Other) using this same medium – photography. Bob, Robin, Sam and Donna enthusiastically accept the invitation to speak photographically to what they see, effecting powerful transformations of some of the original images and creating new images which they provocatively pair with others from the original cluster of chosen photographs. Continuing my engagement with Baer, Derrida and Levinas, this chapter then attends to these transformations as reflective of their taking up of the right of inspection and as an enactment of an ethical response to the call of the Other. Weaving into the discussion questions of wounding and irresponsible visual imagings and imaginings, of voice and speaking-to, I attend also to what new ways of thinking responsibility might be opened up by this work. Now that they have come to see and are no longer able to not see, how do they act? What is it that they do in these transformations?

Marking the Violence

Hearing and answering the address of the Other in the image, a responsible reading is required. Turning to Baer once more, I pay careful heed to his concern that our readings not further victimize the oppressed persons in photographic images produced by more powerful others. It is necessary to attend to the “double difficulty” these readings pose (2002:129). Appending Baer’s caution to the group members’ work, readings of visual representations that aspire to trouble the ableist perspective (and, in this case, readings expressed in and through the group members’ visual transformations of the images) must first be alert to the danger of inadvertently minimizing the violence done to the subjects of the images, either by a trivializing affirmation of survival or the invocation of no more than precarious tropes of the triumph of the human spirit over adversity. Secondly, neither should a reading recall *only* the violence as this positions the persons with intellectual disabilities in the images singularly as passive victims; static, atemporal

and without lives outside the camera's frame and the inscriptions within (Baer, 2002). Either mode of reading tacitly remains an irresponsible account of ableism. The Benjaminian mandate to write from the perspective of the 'vanquished' cannot be fulfilled through a simplistic reversal perspective: a re-reading from below, from the perspective of the oppressed that, in and of itself, offers only part of the story. According to Baer, what we have need of instead, is a critical examination of the visual record, one that "corrodes the comforts of common memory" (2002:129). In that it pushes towards change, towards social and political action, looking is thus transformed into an ethical relation (Derrida, 2001c; Garland Thomson, 2009; Sontag, 2003).

Many of the group members' transformations, their visual responses, speak immediately to the violence that has been/is being done to people with intellectual disabilities and which is represented in and through the original images. But I wish to speak first to the group's transformations of three images that, to my mind, especially unveil the extent of this. Donna's, Bob's, Sam's and Robin's attentiveness to the Other, and to the enormity of the violence depicted in and effected by the *Blatt, Arbus* (Donna's version with the KKK) and the *David* images (the second transformation that removes the body of the man from the image) is unrefusable.

The power of these three transformations is their effectiveness in making "real (or "more real") matters that the privileged and the merely safe might prefer to ignore" (Sontag, 2003:7). In this case, it is the violence, the subjugation, and the consequences to people with intellectual disabilities of unquestioned assumptions reflected in and perpetuated by visual imaging. It also derives from laying blame and placing responsibility with non-disabled others, thus making, perhaps, less easy a non-disabled belief in having somehow been absolved (Garland Thomson, 2001). Defying the non-disabled viewer's expectations as to what will be/should be contained

within/by visual representations of intellectual disability, I would argue that the transformations reflect the im/possible: that contrary to long-held and tenacious beliefs – contrary to “common memory” – people with intellectual disabilities *can* understand public photographic images, *can* think about them, *can* respond, and might very well have a very specific reaction to them – one that actively opposes that of the non-disabled other. In fact, the force of these new images derives primarily from their very clear and active opposition and resistance. The transformed images are thus a surprise.



Seeing and speaking about the *Blatt* image from inside their own experience, the group members’ work reveals a number of possible surprises for the non-disabled other. One is that Bob and the others do not see the un-care of people with intellectual disabilities as acceptable, as justifiable on any terms. That they see it as violent marks their perspective as being different from an ableist one. The physical capture of the child (in a straightjacket, restraint chair, behind bars) and her visual capture (within the ableist frames of the image that hyperbolically mark and stigmatize a dangerous and unknowable difference) have, from the group members’ perspective, been arranged solely to summarize the ableist triumph (Butler, J., 2004). Conversely, the group members’ visual response to the original image demonstrates that they, this group of four persons with intellectual disabilities, are not so captive, not so restrained nor controllable but are, instead, power-full and are exercising this power by (at least, metaphorically) punishing the

punishers; inflicting upon the non-disabled other the types of violence which have been/continue to be inflicted upon them and other people with intellectual disabilities; retaliating on behalf of the child in the original image. In this visual response, they have reversed the viewing positions that structured the original image. Positioning themselves, as people with intellectual disabilities, outside the frame as producer *and* as the unrepresented viewer, they are now “the one who looks on, the one who is captured by no image at all, but whose charge is to capture and subdue, if not eviscerate, the image at hand” (Butler, J., 2004:143). They have accomplished a ‘capture’ of the non-disabled other within the frame (both as viewer and producer) and, in many ways, have done so in precisely the same manner that the child in the original *Blatt* image has been captured.

Looking at this transformation, the viewer’s eye is powerfully pulled towards the same markers of violence that so strongly repelled Sam, Donna, Bob and Robin. But what distinguishes their capture from that of the original is that the group members further believe themselves to have depicted the essence of those non-disabled others who would do this to a child – to *anyone* – with an intellectual disability. They have, as a result, captured – made their own – the meaning of the image. Their re-imagining and re-imagining thus draws attention to the enormity of the violence yet also does more. It makes plain the im/possibility of the original: the possibility *and* the impossibility of a viewer seeing naught but an ableist aesthetic, that which the non-disabled producers want them to see (Baer, 2002). It is the possibility of seeing power. For the non-disabled other it is that the (previously) contained and containable person with an intellectual disability might not be so easily captured. It becomes impossible to see them as without author/ity. It becomes impossible to see them as so very different from themselves (as ‘non-human’ to their ‘human’): people with intellectual disabilities are something other than what they

thought. But this works both ways for it also becomes impossible for non-disabled others to see themselves (at least their actions) in the same way – their treatment of the child points to their own inhumanity. For the intellectually disabled viewer, revealed is the possibility for a usurping of the ableist gaze, for an assumption of power (the taking up of power by people with intellectual disabilities and the non-disabled recognition of this power), for the what-has-yet-to-be in visual imagery, the what-has-yet-to-be in non-disabled knowing and relation to intellectual disability (Derrida, 2001c). The original *Blatt* image thus becomes impossible. The viewer's eye, forced to see the un-seen and thus far un-seeable, is thus directed towards political awareness (Garland Thomson, 2009). Opened up is the space of the other – the other image and the Other. Another surprise then is the revelation that people with intellectual disabilities *are* a threat, but *not* for the reasons heretofore believed (e.g., contagion, uncontrolled lust, irrational aggression). They now pose a threat because in articulating the situation (Martin & Spence, 2003), their work shatters the ableist illusions of their unknowing and inability: they *do* know what non-disabled others are doing (through visual imagery, yes, but also in day-to-day interactions and interventions) and they are capable of *and will* retaliate.



The strength of Donna's transformation of the *Arbus* image can be understood to have been effected along these same lines. It is the fusing of the expected with the unexpected, the familiar with the unfamiliar (Clare, 2009; Garland Thomson, 2009) that serves as the source of disquietude in this transformation. The dominant assumptions are that people with intellectual

disabilities do not have knowledge about their world; are incapable of noticing or having interest in events and circumstances outside of, primarily, their biological selves (Fudge Schormans, 2005). It is not expected that they have the capacity to make associations from and to public photographic images. Through the forceful overlaying of the *Arbus* photograph with an image of the KKK, Donna contests such assumptions, repositioning people with intellectual disabilities as knowers while also dramatically undoing the typical non-disabled reading of the scene as readily decipherable (Baer, 2002). Re-enacting (or differently enacting) the discursive gazes at play in representations of people with intellectual disabilities, this re-imagining makes obvious the extent to which Donna and the other group members *are* culturally aware. Further, in both this image and the *Blatt* image, they powerfully exploit the spectacle of the original images in a move with, I believe, the potential to unhinge the non-disabled viewer. Coming face-to-face with all of the (different? same?) faces in the transformed image, the non-disabled viewer's seeing and knowing is disrupted. Quite clearly, people with intellectual disabilities can and do make associations between themselves and the larger world, between the inside of their own experience and the outside forces that work to influence and define their personal experience. As a consequence, they are keenly aware of how they have been visually (and otherwise) constructed and the irrationality and consequences – the irresponsibility – of these constructions. For non-disabled others, this particular transformation, as an act of resistance, makes this knowledge unavoidable and unrefusable.



In cutting from the *David* image the body of the disabled subject, Sam, Robin, Donna and Bob point out that which the non-disabled other may not wish to admit: that these public photographic images are neither innocent nor harmless (Butler, J., 2004; Evans, 1999; Sontag, 2003). In this visual realization of their critique of the *David* image, Sam and the others highlight what for them are the un-truths of the image and the dangers that accrue from such. For them, the original image speaks to the past and to the present – to what has happened and is still happening: people with intellectual disabilities are being spoken for and by non-disabled others. They strongly reject the application of arguments that, for some people with intellectual disabilities, the severity of their impairments necessitates that others speak for them (Kittay, 2001; Yong, 2007). The group members maintain this denial of their right of consent clearly reflects an over-reliance on false assumptions as to their own (in)competencies and (in)capacities and those of people with intellectual disabilities more generally. This transformation of the *David* image makes this issue plain. Engendered by this gaping hole which immediately snags the viewer's interest is the knowledge that they do not agree with this original image, with this visual representation, and they want this made public. This image is not about them nor about the man in the image; they/he did not consent to this; they/he want not to be part of this; and, if they/he cannot be seen 'safely' they/he want not to be seen at all. By so visibly removing the man from the image, he becomes an absent, albeit lurking, presence. Erasing the disabled subject from the image, they disavow any possibility of conjecture of their complicity with the story told by the image and politicize visual representation of people with disabilities. The surprise, I would again argue, is not just that they are aware but that they are opposed. Theirs is very much a moral and a political position on the right to inspection and the right to representation (self-representation and representation of self by others) (Butler, J., 2004), a taking up of the ethical obligation "to think and transform the ethics of [disability] media"

(Derrida, 2001c:45).

Baer, speaking to his belief that the typical historian's response to the Genewein images is to see only the ruination and the death of the Jews captured in them, is troubled by the insufficiency of this interpretation that so "neatly divides suffering and guilt according to who was in front of and who remained behind the camera" (2002:136). In the same vein, Millett writes that critiques of disability imagery tend towards one-sided interpretations of images produced by non-disabled others as dangerously objectifying (2005). Both argue that much more is going on in these types of images. Unpacking this consideration of the group members' work, I wonder if this is what these transformations do. The group members' interpret many of the original images as documentation or 'evidence' of the violence of non-disabled treatment and attitudes towards people with intellectual disabilities. What's more, they evaluate most of the original images they work with as 'bad', as 'un-truths'. Further, in their transformations, they do effect new viewing relationships, ones which re-position themselves as creators (and only sometimes subjects) of these new images and thus behind the camera. These observations evoke Cixous (1993), who counsels us to attend to the risks inherent in creation. Are the group members now similarly guilty of violence towards people with intellectual disabilities? As 'creators' do their transformations re-produce an objectifying violence? Is their critique too limited, too one-sided? Certainly, the transformed images still seem to neatly divide suffering and guilt, and I pause to consider if this makes their work problematic or too simplistic, but doubt that it does. What these three altered images divulge to me is how, from Sam's and the others' perspectives, people with intellectual disabilities are not completely governed by the ableist gaze, by non-disabled understandings of intellectual disability. The agency expressed in these transformations disavows an ableist assumption of the possibility of their complete governability and control.

Not denying the risks of typical disability imagery, they demonstrate, too, that people with intellectual disabilities are more than suffering victims of publicly sanctioned atrocities. The transformations remind – in fact, they insist – that the non-disabled other appreciate that the subjects of these images are/were ‘real’ living persons and that they reference a much larger group of people with intellectual disabilities for whom the exhibition and reproduction of such public photographic imagings and imaginings have important consequences. And, they point to the failure of the original images to completely objectify the disabled subjects within – at least, for themselves as viewers – an outcome Baer (2002) decrees the ethical dimension of viewing images of violence and essential to the troubling of the triumphalist gaze. Exercising the right of inspection, Bob, Robin, Sam and Donna charge the non-disabled viewer and producer with having “failed to hold this reality in mind” (Sontag, 2003:8). This is not to merely create a ‘new normal’, or to expand the margins of that which we understand to be ‘normal’, but to disrupt our very understanding of such binaries: ‘normal’ and ‘not-normal’, ‘human’ and ‘not-human’ (DeShong, 2008). A Levinasian response and responsibility to the singularity of the Other troubles this binary logic (DeShong, 2008) and reliance on such as an acceptable rationale for the violence the group members read in the images.

Writing about images of atrocities, Sontag (2003) and Butler (J., 2004) speak to the potential of photographic images to accuse. As was written in an earlier chapter, Sam and the others speak at length about being inspected and blamed – ‘accused’ - in their lives and the risk of further accusations that might accrue from public images. In that the transformed images explicitly target a non-disabled audience, are defiant and insistent, make plain not only the violence but also their awareness of it and of how unjustifiable this violence is, the group members deploy the transformed images to turn the tables and accuse their non-disabled other – “j’accuse” (Sontag,

2003:16). The transformations intend, not to make the intellectually disabled producer ‘guilty’, but to (try to) make the guilty non-disabled other (viewer and producer) suffer: to show them otherwise thereby pointing to their guilt, a guilt that demands accountability and requires that, now, it is their turn to suffer. While neither minimizing nor recalling only the violence, yet by filling the (non-disabled) sight by force (Barthes, 1981), the transformation of the original images serves yet as a defence against the forgetting of this violence or of those who suffered it (Baer, 2002).

Speaking-to

For Donna, Sam, Bob and Robin, the transformations and taking of new photographs are a means of speaking-to the non-disabled other, returning me to the notion of photography as dialogue, a relation between the ‘I/eye’ and the ‘You’, and their experience of being excluded from it.

Sontag (1977) writes that the photograph, in and of itself, is mute. What “moralists” and the ‘socially concerned” desire the photograph to do most – to speak – is exactly that which it cannot do; something must be added to the photograph to give it voice (1977:108). M.L. Butler (2004) suggests otherwise. In re-imaging photographs, the group members (undeniably ‘socially concerned moralists’) do wish their images to speak; they use their transformed photographs to “see and say, show and tell what we are part of across time and place, and within relations of power” (Butler, M.L., 2004:279). In so doing, they insist the non-disabled other take notice of the violence *and* appreciate them beyond a conceptualization as victim.

Engaging with the original images – speaking as a viewing I/eye – theirs is, arguably, a one-sided dialogue with the (absent photographer and subject of the) images. Yet, it is, too, a dialoguing with each other, and with me. In forging this relational space they subvert notions of their lack of ability or desire to respond individually or collectively while simultaneously and

solidly re-defining themselves as ‘seer’. Doing so, they achieve some success with inserting themselves (and, thus, people with intellectual disabilities more broadly) into the larger public dialogue on visual representation of people with intellectual disabilities. Then, in the absence of opportunity for face-to-face dialogue, they position themselves to speak also from the I/eye of the producer, the creator of these new or different images. They use their productions as a means of making a political and moral address to the outside, to their other; of speaking-to the absent non-disabled producers and viewers of the images. Importantly, they also address other people with intellectual disabilities. Both subjects of their address indicate a speaking-to that comes, not only, from their own (viewing and producing) I/eye, but also from a position of solidarity with the oppressed subjects of the images (Sekula, 2003). It is a speaking which takes into account that which has remained invisible; the irrecoverable voices of the people with intellectual disabilities within the images (Phu, 2005).

Writing the wrong.



One mechanism employed to speak-to non-disabled others in these transformations are the group members’ re-captioning of the *United Way*, *CAMH*, *Tracy* and *David* images. Let me first address what they do with the *United Way* image. The subjects of this image are nameless. While the caption gives voice to the image (Sontag, 1977), it would seem obvious that it is not their voice; that the words used in the original caption are not their words. (Remember, they are (falsely) assumed incapable of (such) words). Thus, they are doubly (or is it triply?) silenced.

Un-named and silenced, the dis-abled subjects are dehumanized – inattentive to this other, the disabled producers of the images do not speak to, listen, or respond to them (Derrida, 2001c). Countering this lack of response with their own response, the group’s re-writings of the original caption “What’s wrong with this Picture?” dramatically alter the reading of the image. The two new captions are each an explicit address to the non-disabled other. “Don’t take our picture without permission” takes aim at any photographer. “Don’t call us retarded” targets all non-disabled others, irrespective of their viewing position. Much is accomplished in a rather simple and straightforward way. The subjects of the image are re-figured: no longer mute, passive, unable, they now appear to speak and to demand both to be heard and obeyed. Smiling faces reflect not an innocence born of a lack of intelligent awareness of one’s situation, but signify (self) recognition as a knowing subject, a subject speaking for self. Their words make false socially active presumptions of lack of awareness, desire, and competence. The disabled subjects’ (supposed) plea for (at best) benevolent care is replaced with an unequivocal demand for respect. Let me return, for the moment, to Sontag’s cautions on the limits to the photograph’s capacity to ‘speak’ (1977). Exercising their own (individual and collective) voice(s), the group members understand that, in fact, the subjects of the image continue to be silent. They know it is they who ‘give voice’ to these subjects through the captions; that, for all intents and purposes, it is really their voice that is articulated. Such a move contravenes a Levinasian understanding of the singularity of the Other, of the impossibility of speaking for the Other (Levinas, 1998). But, speaking from their own position and experience *as* persons with intellectual disabilities, they are convinced this is what these subjects *would* say if given the opportunity. The new captions then are intended to reflect the missing voices of the dis-abled subjects of the image (even if what they actually reflect are the missing voices of Donna, Sam, Bob, and Robin). In a symbolic way then, these heretofore silenced subjects subjugate the non-disabled producers of the original

image by ‘speaking’; dictating to the now silenced non-disabled photographer and viewer the telling that is to be told, the doing (and not doing) that is to be done (and not done). Sontag writes: “Only that which narrates can make us understand” (1977:23). This transmogrification of the typical viewing relationship in disability imagery accomplished by these re-imaginings makes room for a disabled narrative expressed in these re-sayings, the saying of the unsayable, the forbidden other of the original.



In an ostensibly more gentle (albeit still didactic) manner, the group members’ re-captioning of the *CAMH* and *Tracy* images similarly serves to instruct the non-disabled viewer as to what must be understood (that people with intellectual disabilities can speak for themselves, that they know what they need) and what must be told. In the *CAMH* image, the viewer is told that people with intellectual disabilities do not need segregation, they need individualized educational supports. In the *Tracy* transformation, they are told all of what she believes she needs in her life. Countering the charitable and social control underpinnings of the originals, the *CAMH*, *Tracy* and *United Way* transformations become politicized acts of (self)advocacy soundly rooted in personal experience. And, like the *Blatt*, *Arbus*, and *David* images, they surprise. But the *CAMH* and *United Way* images seem to do more. In both of these images it is this re-captioning alone that serves to disrupt the original, for none of the disabled subjects in the images was altered in any way. The new captions demonstrate the power of text, of words, in the meaning-

making process (Barnaby, 2005; Phu, 2005; Sontag, 1977). Especially for the *United Way* captions, there is no mistaking their intent: the group members want nothing less than to re-organize non-disabled understandings. Attaching these different words to these images dramatically alters viewers' reception, interpretation and positioning of the (dis)abled subjects within.



Looking at their multiple re-imaginings of the *David* image, Robin and the rest of the group similarly twist the meaning of the original image by creating different captions or re-using the original caption in a new way – appending the original text to a (simply or radically) altered visual image. For example, affixing the original caption, “*David means beloved*” to the transformed image of the disabled subject covered with a blanket re-defines what it means to be ‘beloved’: it means the demonstration/presence of care and love, not the absence of such that the man’s nakedness and aloneness implies. It re-defines what it means to have an intellectual disability: it means one is human. Their visual response reflects the group members’ care, their caring about and caring for this Other. Opened up are new forms and spaces of hospitality and new ways of thinking about responsibility. Metaphorically extending care and hospitality to the man in the image through the covering of his body with the blanket, the group’s additional use of this text, addressed as it is to the non-disabled viewer, insists that such hospitality *must* be extended. It becomes a moment of resistance to the spectacle (Barnaby, 2005) that (the group members believed) was the original, one that un-fixes and re-presents the disabled subject.

When considered alongside their conversations about the photographer's decision to take *this* photograph, their re-imaging and consequent re-imagining serves as counter-interpellation of the photographer, a questioning and challenging of the photographer's choices.

Re-imaging the subject of the *David* image in new settings with new captions explicitly addresses the photographer but also the viewer; telling viewers that *David* (*and* the group members, *and* people with intellectual disabilities more broadly) is much more, something other than they supposed or than the original image intimates. The re-working of the subject on a beach with the caption "*David means adventurous*" is another example. Once again, the potential is created for the image, but primarily for the body of the subject (as an inscriptive surface to be inscribed otherwise). This particular transformation, when paired with their many other transformations of the *David* image, demonstrates how their own work, their own 'travels' with the image(s), reflects, too, this sense of adventure.

To trouble the above reading (for I fear it may come across as being a bit too pat) let me return to Derrida for a moment. He proffers the right of inspection entails (if not, indeed, demands) a telling of 'innumerable' stories. At the same time, he attests to the limits imposed upon the numbers and types of stories told. Reflecting Baer's concern with the prescriptive nature of some photographic production and noting as well the intertextuality involved in the storying of images, Derrida would seem to agree with Crary (1990) and Burgin that "(e)ven a photograph which has no actual writing on or around it is traversed by language when it is 'read' by a viewer" (1982:144). Nonetheless, Derrida also articulates how the addition of a written text, by filtering out particular possible readings, most powerfully forecloses on this right to tell innumerable stories. The text (*any* text) works to delimit the image to a single meaning, pushing the viewer to look at and see things as the photographer intended: it "exposes" and "disposes"

the viewer to a very particular reading (Derrida, 1998:7). Contextualizing a photographic image, a caption operates at the level of ideology to make an image intelligible in a specific way (Phu, 2005). Consequently, the captioned image actually hides far more than it could ever ‘expose’.

Certainly, one could understand that to be what is happening here. Robin, Sam, Bob and Donna are seemingly intent upon countering one proscribed and prescriptive meaning with another (others), with an other that is spoken from their disabled perspective. They are quite determined to create new scenes of instruction (Mauer, 2005); to anchor the reading of the image (Burgin, 1982) through the addition of their *own* captions. In Derrida’s words, “You have the authority to tell yourself *these* stories but you cannot gain access to ...that other one” (1998:1). In light of the disjuncture between the transformations and the originals, exposure to the counter readings enacted via the group members’ addition of new captions may, in fact, prove disruptive for the non-disabled viewer. But, the new directives written in and by these new captions may equally be argued to still be reductive. They are, too, reflective only of the voices of these four individuals – Robin, Bob, Sam, and Donna: what Phu termed the “irrecoverable voices” of the subjects of the original images have not been recuperated (2005). It might not, however, be quite so limiting. For Phu, recovering these voices is not the point – speaking to their loss is and that would seem to be one of the things effected here. The group members’ use of captions might then be less a function of their own ‘speaking for’ than of speaking about these missing voices and speaking against a non-disabled ‘speaking for’. Derrida himself goes on to suggest yet another alternative understanding. The use of multiple captions for both the *United Way* and *David* images makes especially plain the ambiguity of the visual image, the troublesome institutionalization of meaning, and the ease with which both can be manipulated (Phu, 2005),

possibly reminding the viewer of the potential (inherent in every photographic image) for multiple readings. As Derrida writes (and, as I stress with Sam, Bob, Donna and Robin), “Each to their own stories, I shall leave you to yours, you have a right to look” (1998:1).

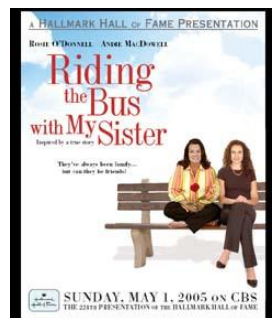
Pursuing this thread, I am drawn to Phu’s (2005) description of the work of visual artist Theresa Hak Kyung Cha as a “relationship between image and text that attempts to escape the trap of captioning” (2005:30). Cha was concerned to disrupt the ideological foundations of explanatory texts. Her pairings of images with seemingly unrelated texts, with counter texts, makes the images un-intelligible. In a similar fashion, the group members’ counter captioning (even when these captions might similarly be interpreted as explanatory) of a single image, especially when considered alongside their multiply disruptive forms of re-captioning across the images as a group, highlight how the original images with their explanatory captions are representative of only (at best) a fragment, and not, as is more often believed, the ‘full reality’ (Sontag, 1977) of intellectual disability. As such, the indexicality, the ‘truth’ of the original image is thus both rendered and revealed to be unstable^{xxi}. In this way, Phu’s thesis shares much with the work of Baer and Butler that I have been using here. The original images become un-intelligible or, at least, less readily intelligible. In and of itself, recognition of such might work towards an unsettling of not only what we are given-to-be-seen in visual disability imagery, but also, more broadly, taken-for-granted and unquestioned ideas about people with intellectual disabilities.

Speaking to the power, the influence, and the responsibilities of visual media, Derrida (2001c) proposes the ethical question that needs to be asked is this: “What should be our duty in these circumstances?” Answering himself, he suggests (like Baer (2002)) the need to cultivate a critique, to be suspicious of what we are given-to-be-seen, and “to complicate, to introduce heterogeneity within this more and more hegemonic structure” (Derrida, 2001c:45). The group

members' many re-captionings make apparent that what can and cannot be 'taken' about intellectual disability from the images is far less clear cut than may have previously been believed. As a condition of possibility, the multiple captions create multiple encounters with the images. By highlighting this ambiguity the transformed images are thus an expression of hospitality, an invitation to alternative readings that can reconfigure the disabled subjects within and broaden the non-disabled others' knowing of intellectual disability.

Returning the gaze.

A second way in which Donna, Bob, Sam and Robin 'speak-to' the non-disabled other is through transforming the images in such a way as to have the disabled subjects gaze back. Such a looking back is also a means of dialoguing across the space between the images' borders and the viewer. What is at play then is a refiguring of not only whose eyes are determining what can and cannot be seen, but also whose eyes are looking back: a new 'we' who is looking, seeing, responding, and telling.



Let me start with the group members' work to re-visualize the actress playing a character with an intellectual disability in the *Rosie* image. In the original she is staring off to the side and the visual dialogue collapses (Hevey, 1997). The group members felt it critical to re-direct her gaze squarely towards the camera/viewer – not necessarily to make her look 'normal', or 'not-disabled', but to make her look like them, (and) like people with intellectual disabilities. As I

wrote earlier, they know no-one with the ‘dreamy’, disconnected and unaware look configured by the photographer for this character. Quite simply then, this is, for them, not a truthful representation, merely the signature of the oppressor (Phu, 2005). The transformed character’s gazing back from within the image’s frame seems to work both as a corrective reply and as a challenge (Wright, 2001) to the original to undermine the sublimating power-over of the non-disabled gaze and the related difference in status the original creates/determines between this ‘disabled’ character and the un-disabled woman in the image. What is most surprising is that, in exposing the insufficiency of the original image, the transformation of the character with a disability serves to re-invent them both. Through this re-posing of the disabled character (both her ‘look’ – more professional, less stereotypically disabled’ – and her ‘looking’ – like the other woman, evenly at the camera), ‘position’ and ‘supposition’ also shift. The relationship between the two women is re-ordered. The dichotomizing distances – able/unable, powerful/powerless, child-like/adult – shrink, fashioning a new ‘place’ for each in the image. Baer (2002) asserts that the subject’s looking-back works to deflect her/his objectification and implicit subordination to the gaze of the more powerful photographer and viewer. It subverts and undermines the triumphalist photographer’s desire to completely own the depicted scene. Used here, the woman can be understood to be saying, “Yes, you can look, but know, too, that I am also looking.”



Masks - as instruments that block or obfuscate the subjects’ ability to look or to be clearly seen

and seen as looking back – prove an important element to be transfigured in two different images. The first is Bob’s poignant transformation of the *Arbus* image, his insertion of an image of his beloved (and now deceased) girlfriend, L., into the original. As with the *United Way* image, none of the subjects are named. Neither is there a caption – no words are spoken. Lacking a clearly articulated narrative, the image takes on a sinister, spooky quality (Shields, 2004). All of the women in the original image are masked and, in the further absence of names or words/voices, our knowledge is confounded: the viewer cannot know ‘who’ is depicted, only ‘what’. Foreclosed, too, is the desire to try to know the other. Such depersonalization dehumanizes and, in the Levinasian sense, effaces that which is human (Butler, J., 2004). While the women’s faces are directed at the camera, their eyes are difficult to see as a result of this masking. Their looking-back is restricted, less certain. Bob chooses to metaphorically un-mask the women in his decision not to cover L.’s eyes – to expose her - and, as a result, her gaze more assuredly meets that of the viewer. Returning to Baer’s thesis, he writes that “returned glances mark the camera as a tool that cannot be entirely subordinated to the intentions of the photographer” (2002:169). Bob’s transformation (while clearly a manipulation of the original) seems to speak to the failure of the original to completely capture this woman (L.) and the other women with intellectual disabilities within. Levinas cites this as a failure of all representation. In that representation belongs to the sphere of objects, the relation to things, any representation (or re-representation) is able only to show a ‘what’ and not a ‘who’ (Levinas, 1969; Pane, 2005; Perpich, 2008). And while Bob’s transformation does not reveal who L. is, in the Levinasian sense of her singularity, his transformation does point to the failure of the image to subordinate her and the other women in the image to the ableist perspective depicted in the scene of the original. L.’s gaze, as representative of the hidden gaze of the other women, serves as a counter to what we are given-to-be-seen; the common memory associated with disability imagery. In

that it belies disabled subjectivity as necessarily that of ‘victim’, it is also both challenge and accusation (Wright, 2001).

Speaking to one particular historical photograph of Native Canadians, Lippard, observes that the subjects of the image do not adhere to the ethnographic ‘rules’ constraining photography of Native Canadians during this historical epoch. What astonishes is that the three subjects (father, mother, child) look back at the (white female) photographer (and at Lippard as viewer) warmly, with an “open, intelligent gaze” (Lippard, 2003:346). L.’s gaze is startlingly similar. (This is likely explained as a function of the photograph’s origin – taken by someone in the group home where she lived and with whom she shared a relationship.) As with the Lippard image, it signifies a reciprocal moment: interaction, communication, and exchange (2003). L.’s gaze bespeaks the possibility of knowing, but of knowing otherwise. It appears as an invitation of the non-disabled look (even of the stare (Garland Thomson, 2009)); an invitation to look again, to think differently, to re-consider. Bob seems to be saying that if the intention of the non-disabled photographer (Diane Arbus) was to visualize intellectual disability as a ‘bad’ thing, and people with intellectual disabilities as unable to know beyond this simplistic and child-like view of the world or to be known beyond ‘freak’, then she got it wrong.



Garland Thomson (2009) writes that the photographic image affords the non-disabled viewer the opportunity to stare ‘safely’ at atypical bodies, a venue guaranteeing they need never (at best) or

rarely (at worst) come face-to-face with, or have to engage with, a disabled person. It thus seems feasible to do as Clare (2009) does and make the leap to assuming that the masking or blindfolding of a person with an intellectual disability in a photograph provides another layer of ‘protection’ for the non-disabled viewer. The figurative blindfolding, the covering with a black band of the child’s eyes in the *Blatt* image transformation, can thus be interpreted along two contradictory lines. This well-established photographic contrivance was originally invoked to safeguard the confidentiality of the subject of the image – masking the eyes masks one’s identity. In disability imagery, however, Clare argues this photographic device contrarily protects the non-disabled viewer from ever having to confront the gaze of the disabled subject, or from the ‘seeing’ of the subject that may be realized through the seeing of the subject’s eyes (2009). Re-taking this image with a non-disabled subject/object, the group members’ subvert this non-disabled privilege by making plain how the privilege itself has been constructed. Prohibited from looking back, the non-disabled subject in this re-imagining is, like the child in the original, prevented from looking, speaking, or telling. Confined, subdued, no longer a ‘seer’, he is re-positioned in the opposing/opposed positions of ‘seen’ and as ‘seen-as’. Blindfolding the non-disabled subject/object this way, he is also rendered mute: unable to gaze back or respond. In that the image suggests that the child has been removed from the situation of the original, that it is (symbolically) she who has turned the tables, who has effected this capture, it is also implied that she has been un-masked, enabled to see and respond and, through this counter image, to be, herself, seen differently. In this sense, this image, too, is accusatory as well as redress.

The group members’ re-directing of the subjects’ gaze, and their (un)masking of the subjects in the transformations, makes plain the group is keenly aware that they, as disabled persons, are constantly looked at, constantly inspected, constantly evaluated. The transformations become

the avenue by which they claim, now, their turn to do the looking, to gaze back as a means of making their knowledge known to the non-disabled viewer. The alterations to the *Blatt* and *Rosie* image are, I think, quite effective at pointing out the violence of this inspection. Bob's work with the *Arbus* image using his photograph of L. is, I would submit, doing something else as well. In this transformation, L.'s looking is a looking back that acknowledges the self and also the self-in-relation to the people in the images. For Bob, identification as a person with an intellectual disability is, in (the instance of working with) *this* image, positive; a claim he wishes to make – for himself and on behalf of L.. L.'s looking back hints at two things I believe he wants the viewer to recognize. The first is this re-evaluation of the unquestioned 'fact' that having an intellectual disability is bad, undesirable, the worst thing that could happen, and that all people with intellectual disabilities (if able to understand anything at all) understand this to be true. But I feel Bob is taking this further, adding emphasis to this while simultaneously saying more, and I will rely on Hevey's discussion of Arbus' work (1997) to explain this.

Hevey argues that Arbus puts forth "the factual recording of disabled people as freaks", an assertion unproblematicized by the majority of her non-disabled critics (1997:334). What was disruptive for non-disabled viewers of her work was not the 'fact' of the otherness of people with disabilities but Arbus' framing of the non-normal in normal situations – 'normal' clothes, 'normal' environments, 'normal' poses and attitudes – thereby making the disabled too familiar. She located the "disabled terror" within non-disabled normality by placing a disabled normality within the non-disabled normality (Hevey, 1997:337). Hevey argues that Arbus' work with people with intellectual disabilities, including the image chosen by Bob, was unlike other disability imagery created by Arbus because the intellectually disabled subjects/objects remain firmly entrenched beyond the conceptual *and* geographical borders of normal; securely

segregated, kept at a distance. Photographed in a segregated institution, in paper and blanket costumes, their posing fails to intrude upon the non-disabled normality. Nor do these costumes challenge their bodies (as is the case with other Arbus images of people with, for example, physical impairments) – rather, they match them (Hevey, 1997). Considering this argument in the context of this discussion, it thus appears that the triumphalist perspective remains intact. The masks can be read, not only (naively) as part of the costume, nor only as (imposed?) restriction of the subject's/object's engaging or engagement with the viewer. Neither can they be merely read (as with the *Blatt* image) as a means of protecting the non-disabled viewer. The wearing of masks must also be understood as inferring that people with intellectual disabilities cannot (proudly) face the camera as themselves – they must hide beyond the costumes and masks. Breaking down the naturalized enfreakment of intellectual disability, trembling the 'protective' features of the mask, and re-claiming a disabled identity, Bob has L. engage with the camera/viewer as herself, a self who is also (comfortably) marking herself (being marked by Bob) as a person with an intellectual disability. This becomes another route by which the image has the potential to surprise. Admittedly referencing, too, the slippage between Bob, L., and the image, Bob's transformation is an attempt to engage the viewer in a dialogue with the express purpose of provoking change.

There is another reading possible here. Arbus (in Sontag, 1977:191) writes of how the camera operates to incite people towards being photographed: "A lot of people, they want to be paid that much attention and that's a reasonable kind of attention to be paid." As noted earlier, the *Arbus* image Bob worked with was drawn from Arbus' work, *Untitled*, a collection of images with no accompanying information on Arbus' processes or decisions in the taking and the making of these images. Consequently, we know nothing about the subjects' experiences of Arbus'

‘attention’ or whether it was even wanted. Thinking back on the group members’ concerns with issues of consent; their worries, fears and objections to disability imagery; their questions around rights and responsibilities, I wonder if the masks can be understood to reflect this (although I acknowledge this may not be what Arbus intended). Un-masking then assumes a different significance and implies a different responsibility – a comfort level exists when the creator of the (transformed) image is someone known, someone trusted. In this instance, attention is welcome because it represents a different kind of attentiveness than what they are used to, an attentiveness rooted in an ethical concern with the Other.

Reclamation



It is in (directing) the taking of their own photographs, with themselves as subjects, that Sam, Bob, and Donna (Robin’s participation is more vicarious) most forcefully insert themselves (and, consequently, people with intellectual disabilities) into the images, into the visual record, and thus into the dialogue. Clare labels such action the “reclamation from thievery” (2009:5), arguing that, for people with disabilities, making their bodies their own photographic subjects is one means of reclaiming and stealing back their bodies (2009). Adhering as they do to a conventional aesthetics of portraiture, in these photographs the group members’ proximity to the photographic image, to the original images, and to the disabled subjects within the original images is re-ordered. Now ‘in’ the images, they disclose their own proximity to ‘intellectual

disability'. Fashioned as they are to trouble many of the original images, the portraits impose a distance between themselves and the originals; and also between the persons with intellectual disabilities in the originals and those original images. In these images (the individual portraits and group shot), Sam, Bob, and Donna adopt a full-frontal pose, confidently and contentedly facing the camera/viewer. No longer running from photographic capture, they exercise the right of inspection to take control of their visual re-presentation, to reclaim their bodies. Privileging their own stories, they choose from the selection of possible images created during their photo shoot the 'best' images, those that will enable them to shape and (to the extent possible) govern the scene/seen (Burgin, 1982); to shape the story. Incorporating their own bodies, their own faces into the new images, makes unequivocal an understanding of the work as political: as a politics of visibility and representation, and as a representation of politics.

A lens for further exploring Sam, Donna and Bob's photographic re-presentation of self is Kratz's work on representation in museum and gallery exhibitions (2002). Her analysis is guided by two themes (which, for me, resonate with Benjamin, Baer and Derrida), which she describes as "interconnected conditions of possibility" (2002:3). The first theme is communicative practices – the kinds of communication involved in representations and the communicative practices through which people negotiate their understandings of them. The second is the politics of representation – the diverse politics of representation that involve people with different kinds and degrees of knowledge, engagement, power, and influence with the result that they are invariably uneven. Inherent in both are notions of identity and difference and, by extension, values and evaluations. Kratz's (2002) intent is to provoke critical reflection on representations, on those historically specific communication practices and politics of representation central to them, and on how our understandings of identity and of difference can

be formed and changed through these processes. She wants to understand how photography might be an opportunity to re-create, re-formulate, or re-present identities, values, social or political priorities. Two central questions asked by Kratz are relevant here: “How do we know and show who we are and who others are?” and, “How do others know us and how might such impressions be changed?” (2002:3).

I would proffer that Sam’s, Bob’s, Robin’s and Donna’s work with the images evinces their active engagement with Kratz’s questions. Their critique and transformations speak to their efforts to both ‘know’ and ‘show’. Their transformations endeavour to ‘change’ the non-disabled one who looks, to disrupt that which s/he thinks s/he knows, the ‘impression’ that has thus far been made. But it feels, for me, as if the intimacy of Donna’s, Bob’s, and Sam’s portraits, the speaking-to inherent in this very personal looking back at the camera/viewer, makes these images an explicit address with a clearly defined purpose. The immediacy of this work is in its depiction of an encounter: it is about looking, speaking and telling from the inside, from the private space of personal experience and identification as ‘disabled’, but it is a telling that is outwardly directed, towards the non-disabled other. Troubling what gets communicated, they have also, to some degree, flipped the communicative practices and relationships of typical disability imagery on its head: re-figured is what is seen, who is seer / seen / seen-as, and whose ‘voice’ is heard. If seen and heard (and they desperately want it to be), they believe this to be a ‘condition of possibility’. No longer is theirs a speaking from a distance, from the ‘safety’ of the position of creator of the transformed images. The dubious and contentious positioning of speaking ‘for’ or ‘as’ the disabled subjects of the original images is abandoned. For the most part, the group members have resisted public disability imagery, regarding it as “some sort of trespass, disrespect, or sublimated cultural looting” (Lippard, 2003; Sontag, 1977:161). Robin is

steadfast in his opposition to visual capture, even that which is under his control. And Sam's, Bob's and Donna's decision to take photographs of themselves is not at all removed from their earlier view that no images are preferred over unsafe ones (expressed in their decision to remove the subject from the *David* image). This attempt to change impressions non-disabled demands of them a significant leap of faith: faith that the non-disabled viewer will read these new images in the way that they intend.

No longer passive, still, frozen, 'done-to' (as is evinced in more typical, colonialist-types of imaging of disabled subjects (Hevey, 1997)), these self-portraits reflect a heretofore unrecognized and (until now) dis-abled agency – a 'doing'. At play are both a politics of representation and a representation of politics. In her essay on Lincoln Clarkes' photographs of female heroin addicts living on Vancouver's downtown eastside, Margot Leigh Butler (2004) raises a question she is unable to resolve: how it is that so many women in Clarkes' photographs are looking back. She wonders what this represents. Is it the women's choice? An expression of agency? Or, the photographer's preferred pose? In this project, the decision to (re)direct the disabled subjects' (their own and others) gaze outwards was made by the group members themselves. The primacy of the looking face – as "the mirror of the soul, holding the visibility of the interiority" (Bal, 2004:5) – seems a factor here. Possibly (very probably) reflecting the influence of photographic aesthetics of portraiture (and what Bal (2004:7) terms the "discourse of the face"), it nonetheless represents their attempt to create an encounter with the non-disabled other. It is an attempt to re-present the self. I wrote earlier of Levinas' objection to representation. Derrida poses another paradox – while representation is a form of violence in that the face of the Other is treated as an object and reduced to a thing, not representing the Other, not attributing to them the "status of an *ego*", is also violent, also an ethical failure

(Derrida, 2001c; Perpich, 2008:72). For the group members, this attempt at self-representation is in contrast to (and expressing their critique of) the perceived enfreakment of people with intellectual disabilities in many of the original images and in these photographs, the ones they have taken, they believe they are made ‘real’ (Bal, 2004; Sontag, 1977).

Considered from the lens of the discourse of the face, the group members’ deployment of the face (their own faces), standing, as it does, as a self-evident marker of the individual – the *human* individual – seems (unconsciously?) intended to counter their collective dehumanization in photographic imagery. The photographic portrait is typically understood to make value judgements about the photographed individual and also, more generally, about the worth of individuals as a category. If we understand the purpose of portraiture to be in the service of the individual, as a means of articulating the humanness of the face portrayed (Bal, 2004), these portraits function then as both record of, and appeal to, recognition of such. Returning to Sontag’s point that the photographic image ‘speaks’ to the viewer – “Look, the photographs say, *this* is what it is like” (2003:8) – for Donna, Bob and Sam, these images offer a different telling, a ‘truth’ (their truth) versus an (ableist) un-truth. They deploy the images to point out what being a person with an intellectual disability is (for them) ‘really’ like or could (for them and for the disabled people in the original images) be like. (Writing this, I am reminded of the original caption for the *Tracy* image: “Who Tracy might have been.”) And this is achieved by embracing the medium – inserting their own bodies into the image (thus simultaneously accomplishing a metaphorical inclusion for the people with intellectual disabilities in the originals). Either way, what they believe to be achieved is a speaking-to through the images; telling the non-disabled other of their *own* experiences, lives, opinions etc. It is a speaking-to that demands a response. Returning to Baer, “each returned gaze implicitly demands, against the

axiom of Nazi racism [ableism] that we respond to *this* face, that *this* individual is absolutely singular and demands to be seen” (2002:145). This effects an inclusion that counters their historical and contemporary exclusion. Further, a shift occurs in which the more homogeneous ‘people with intellectual disabilities’ is recalibrated to oppose disabling presumptions of ‘same’ and highlight the heterogeneity of persons with intellectual disabilities. It is an inclusion that begins to transform the terms of the dialogue: no longer exclusively ‘looked-at’ and ‘seen-as’, they are looking and seeing and speaking and telling. Revealed then is “power not freakishness” (Clare, 2009:5).

There is much support for this reading of the potential impact of the group members’ staging of their own gazing back. In much photographic theorizing, this gazing back at the camera, back at the viewer when s/he looks at them, appears both to give the subject of the image power and to foreclose on viewers’ voyeurism. It is believed to create an exchange of looks, an acknowledgement between viewer and viewed/viewing subject that counters or counteracts the implicit power relations of looking (Berger, 1982; Butler, M.L., 2004).

Baer (2001), however, appears unconvinced that the returned gaze alone can always be understood to be a disruption of the triumphalist perspective, wondering if (instead? at times?) it is not actually reflective of power-over. Margot Leigh Butler, writing about Clarkes’ photographs of women heroin addicts, is similarly reluctant to claim an emancipatory power for this visually realized looking back in photographic images of oppressed and marginalized persons (2004). Her doubt, like Sontag’s (1977), stems from a recognition that this remains, after all, *just* a photographic image; there is no ‘real’ dialogue, conversation, speaking-to (and thus no knowing (Bal, 2004)) possible; and, in this ‘exchange’, the viewer continues to prevail, as s/he is still very much in control of whether s/he looks at or looks away, of how s/he looks and

how long s/he looks (Butler, M.L., 2004). Despite what may be intended by its production, photographs “can have a wide range of meanings and interpretations, and may also “hail” or interpellate their viewers differently”, and we can neither pretend away nor disavow this fact (Butler, M.L., 2004:287). This gives me pause, and (with no little anxiety) I wonder, “Are the group members’ images any safer?”

Reading Butler, her concern that as an “over-used trope and device in images” the returned gaze is “completely exhausted” (M.L., 2004:291), I worry the group members’ risk is for naught. But Butler goes on to suggest that if a subject’s gaze is strong enough, or surprising enough, it might be sufficient to activate the returned gaze, to trigger its ability to disrupt (M.L., 2004). This compels my gaze towards Bob’s portrait. Like that of Sam and Donna, the staging of Bob’s portrait adheres to long-standing conventions governing the structuring of a photographic portrait. The image centres on his upper body and head and he is photographed in a relaxed, casual pose. Leaning forward, however, Bob is visibly speaking in his portrait, addressing someone outside the image’s frame. His hands are also implicated in this speaking; gesticulating, they too are deployed in his address to the unknown non-disabled addressee. From my looking position (my knowing of Bob, my familiarity with how he communicates and converses with others), he seems to be asking the addressee to consider something (though present for the making of the image, I cannot now recall what). It is this detail that evokes for me the strength, the substance, of his returned gaze. The looking back engendered through the group members’ many transformations and Sam’s, Bob’s, and Donna’s portraits demand that they must now be regarded as “someone (like us) who also sees” (Sontag, 2003:72). The interruptive force of Bob’s portrait is the additional demand for recognition as someone who also speaks.

If, in one's reading of the photographic image, one can "violate its silence, you break the law, the command of silence that presides like a categorical protocol over the whole ceremony" (Derrida, 1998:1-2). Extending (by countering) the knowing that is possible through the visual in their taking up the 'right of inspection', the group members' critiques, as well as their transformations work to disrupt the more powerful ableist perspective (Baer, 2002), and a taking-for-granted of the rules and uses of disability imagery in the production of cultural meanings and values that sustain relations of domination and subordination (Evans, 1999). In their encounters with the images, they painfully come up against the irresponsibility of disability imagery. Taking up the responsibility of inspection, they unveil the forbidden readings, the im/possible narratives (DeShong, 2008), and thus move towards a breaking of the silence; a breaking of the power of the silence – the power of the constructed nature of the disability image – and of the power held by the non-disabled producers of these types of images. Re-positioning themselves – as the one who is observed but who also dictates the terms upon which they are observed – they re-take these photographic mis-takes, they make the images their own, thus subverting their meaning and calling into question unquestioned assumptions about intellectual disability.

MAKE

ME

THINK

ME

SECTION 4

Chapter 16 – Make Me Think Me

Introduction

Did you like our work? Did you think I did a good job? How was my reading, was my reading good? (*Donna*)

The piece by visual artist Bruce Nauman (in Sillars, 2006), featured on the previous page, presents against a plain white backdrop, four hand-written words – all capitalized, no punctuation – on four lines, a single word for each line: MAKE ME THINK ME. Writing about Nauman, Sillars (2006:12, 14) observes that his art reflects his interest in the “functional edges” of language, the places where language starts to break down as a useful tool for communication, and that his “simultaneous combination of multiple, and often contradictory, information in and through texts is a deliberate ploy...to remove fixed function or meaning”. Resonating as it seems to so clearly do with critical disability theory and Derrida in its emphasis on language and the fluidity and fragility of meaning, I also read in these words questions of responsibility. Viewing Nauman’s piece, from my position as a Ph.D. student in social work, deeply immersed in my doctoral research project, I was struck by the manyness of meaning possible in these four words and four lines – possibilities that spoke to some of the complexities that emerged in my own work, and which were captured in Donna’s (proudly spoken) questioning of the audience at an art gallery presentation of the work she, Bob, Sam and Robin, created. Of relevance here, such possibilities further direct my attention to the implications of the work for social work.

What I will do in this final chapter is to consider three of the meanings possible in Nauman’s piece, three ways that I read ‘MAKE ME THINK ME’ in relation to the work of this research

project, which suggest to me implications for social work(ers) with people with intellectual disabilities. The first concerns the ableist construction – the making and thinking – of people with intellectual disabilities as dysfunctional. The second considers the re-construction – the re-making and re-thinking – that can occur when people with intellectual disabilities have the opportunity to undertake a critical analysis of, and public response to, the ways they have, as a group, been made and thought by non-disabled others. Finally, I wonder what might be social work’s responsibility to its own ‘making’ and ‘thinking’ when inspected under the light of Donna’s, Sam’s, Robin’s, and Bob’s work.

Make Me (Dysfunctional) Think Me (Unable)

As was starkly evident from their very first encounter with the public photographic images, Bob, Sam, Robin, and Donna were struck by how people with intellectual disabilities (and, by extension, they themselves) were so violently and erroneously mis/taken in most of these images – typecast as dysfunctional, beyond the limits of knowable, and undesirable. For the most part, they strongly disliked the public photographic images they worked with. With few exceptions, their reaction was one of disappointment, anger, upset and opposition. They felt the images revealed that people with intellectual disabilities “are not wanted”; neither cared for nor cared about. The images portrayed people with intellectual disabilities as “frightening”, “different”, unlovable and powerless – the last thing anyone would ever wish to be yet unlike any person with a disability they knew. They evoked for group members recognition of dominant devaluing attitudes towards people with intellectual disabilities – the disrespect and disregard they themselves experience daily (and from which social workers are not exempt). Despite this recognition, revealed was their unpreparedness for the force of these images that they had, hitherto, paid scant attention to and the power of visual imagery on their own experience.

Resisting and opposing what they saw, internalized ableism is, nonetheless, one possible outcome of these cultural influences on non-disabled knowing of intellectual disability – (*You Make Me Dysfunctional (I) Think Me Unable*). As I wrote, each of these four people had, and continue to have, untold experiences of marginalization, discrimination and oppression. While quite able to talk about these experiences and to recognize them as unfair, they had all, to greater or lesser degree, internalized these dominant, ableist understandings of intellectual impairment as a tragedy, a personal problem, and of people with intellectual disabilities as somehow lesser (Aull Davies & Jenkins, 1997; Campbell, 2008). None of the group members wanted to have an intellectual disability. They sometimes struggled with their need for support. There was a tension between feeling good about themselves (which they very often did) and dealing daily with (often very extreme) prejudice. Recognizing themselves in the image was painful and necessitated an active pushing against this recognition. Not recognizing themselves similarly provoked a pushing away. Both demanded resistance and the need to distance oneself from the disabled figure in the image, from the social constructions of intellectual disabilities represented by and in these figures; to, at times, actively resist the imposition of these constructions that do not fit (Watson, 2002) and, at other times, to try to hide or mask one's own impairment – to pass and/or resist being seen as being the same-as the figure in the image – as a means of caring for the self.

What is critical to point out here is that social work(ers) have similarly been inattentive to visual (and other social) representations of intellectual disability, and to their impacts on labelled people, and have accepted these and other dis-abling discourses of intellectual disability largely without question (Mackelprang & Salsgiver, 1996; Oliver & Sapey, 2006): disability is “beneath notice” (Titchkosky, 2003:216). Both the research literature and the group members' experiences

of professional help articulate this. Solomon (2007:100) writes of social work: “caring takes thinking and thinking takes caring.” But, to a great extent, social work caring would seem to remain rooted in an expert professional thinking, one that is entangled with medicalized, deficit-based notions of disability. The emphasis is still on taking care *of the problem* of disability instead of caring *about*, attributing value, and finding a place for people with disabilities (Fawcett, 1998; Grant & Cadell, 2009; Oliver & Sapey, 2006). The possibility of recognizing the gifts inherent in relationships with people with intellectual disabilities is lost amidst the search for cures and fixes (Hall, 2007). Emphasizing diagnosis, social working from this perspective locates disability in the individual, thus ignoring the external social, political, economic, linguistic, and cultural factors involved in creating disability *as a problem* (French Gilson & DePoy, 2002; Titchkosky, 2003). The experience of intellectual disability is thus understood as a function of the impairment. Social work’s own implication in the creation and perpetuation of the ‘problem’ of intellectual disability and the ‘problems’ faced by people with intellectual disabilities is thus conveniently masked.

We are cautioned as to the limits of, and potential violence inherent in, all ways of knowing, and the concomitant imperative of deconstructing both our means of knowing and our knowledge claims (Kratz, 2002; Simon, 2003). Speaking specifically to social work and our (often unquestioned) conviction that social work ethics can effectively guide our thinking, knowing and doing, Rossiter similarly suggests this potential for violence “coexists with the possibility of justice found in our conclusions” (2006:139) – we may believe that a concern with social work ethics ensures ethical practice, but this is undoubtedly less assured than we might hope it to be. Grant & Cadell (2009) assert that we must attend to the pain created by our ways of knowing and intervening. To that end, the work of Sam, Bob, Donna, and Robin seems to suggest that social

work(ers) look closely and carefully at what is known and what is done in the name of ‘helping’ people with intellectual disabilities. Intellectual disability, as a construct and an experience, is not fixed, static, or unmoveable – nor should our conceptualization of intellectual disability be. We must constantly engage in a reflexive re-definition of disability and people with disabilities according to changing knowledges, contexts, and cultures (Corker & French, 1999). A more useful approach is to adopt an attitude of incredulity towards those dominant discourses and meta narratives of disability, inscribed in visual representations and elsewhere, that are proving so violent. John (1994) writes that such incredulity can act as a refutation of and resistance to the way these narratives re-present the so-called ‘reality’ of intellectual disability. Social work(ers) must be more keenly aware of both the discursive logic and prescriptive practices in social work itself; those that shape our attitudes, perceptions and interventions (policy, practice, and social work education) with ‘Others’. As well, we must not fail to recognize the relativity, instability, and indeterminacy of meaning of such; and the potential for harm inherent within. Writing from a Levinasian frame, Rossiter argues that social work is constantly engaged in a search for the *right* theory, the *best* response: we are convinced that we can definitively ‘know’ the Other, and that there is an answer as to “how to practice”, a singular right way of social working. Calling into question this notion of a ‘right way’, she nevertheless agrees with the need for an ongoing questioning of social work: not to arrive at an inevitable “Practice Answer”, but to keep us alert to the ways in which our knowing, our thinking, our doing may, in fact, be doing harm (2006: 140). What do we mean by ‘intellectual disability’? How do we regard and understand the lives of people with intellectual disabilities? Just what is it that we are doing in our practice with people with intellectual disabilities? Are we actually helping? How is it that we are implicated in the oppression experienced daily by labelled people? Why, despite our profession’s stated goals, values, and ethics, do people with intellectual disabilities still appear to

be so devalued? What could we be doing otherwise? We need to pay attention to our thinking about disability, and to our everyday interactions and communications – to what it is that happens in the space between social workers and people with disabilities; the space between human beings (Treacher, 2006).

Make Me Think (about) Me

Engaging people with intellectual disabilities in a critical project about how they are represented in public visual imagery, this research was intended to address and redress the historical exclusion of people with intellectual disabilities from research, from the production of knowledge that guides social work practice and policy (Fawcett, 1998; Grant & Cadell, 2009; Ward, 2009). As noted by Warren and Boxall, the most socially excluded people (such as people with intellectual disabilities) are also the most likely to be excluded from the academy (2009). Creating a space for a new kind of engagement with people with intellectual disabilities, I asked group members to think critically about how they have been visually imaged and imagined, their understandings of the reasons for this, and the effects of such on their own lives. As became quite clear, the work being asked of them was oft times quite painful but not defeating nor, did it seem to me, to effect any long-lasting discomfort. This research (arguably, like all social work research should) was guided by my desire not to do harm, not to cause pain, and it was not without some anguish that I witnessed and experienced the depth of Sam's, Donna's, Robin's, and Bob's emotional responses to the work. Grant and Cadell (2009:) suggest, however, that social work(ers) should begin to look differently at the 'pain' that may result from difficult experiences: rather than attempting to avoid or eliminate it altogether, "(w)e need to understand that pain does not necessarily destroy one, and that those facing challenges have the ability, *when they have access to resources*, to endure these challenges" (Grant & Cadell, 2009:429, *italics*

added). It is this access to resources that is likely key – many supports were built into this project (although, at times, I still worry over their adequacy); supports provided both by me and by the group members to each other. While painful at times, I am not convinced that Bob, Sam, Robin, or Donna would have benefitted more from *not* participating – quite the contrary. As I will address shortly, a number of benefits accrued from their involvement in the project, benefits that have extended far beyond the life of the project itself.

This does not mean that I advocate anything other than carefully considered processes and opportunities for social work engagement with people with or without intellectual disabilities in research. This project included only four people with intellectual disabilities, four unique individuals with some commonalities (e.g., the label ‘intellectually disabled’, similar experiences of oppression) but many differences. Keenly aware of the heterogeneity of those having been assigned to the category ‘intellectually disabled’, one cannot in good conscience suggest that *all* people with intellectual disabilities would choose or be able to participate and respond in the same way, with myself or with another research, in a similar or different context. Indeed, it is such sweeping generalizations that are at issue in the field of disability studies. What I do mean, is that social work researchers might do well to reconsider their generalized objections to, and dismissive discounting of, more active involvement of any/all people with intellectual disabilities in research and the production of social work knowledge; to analyze the origins of such exclusionary ideas (be it the notion that they lack the capacity to participate and/or that they need to be sheltered and protected) in order to better understand the outcomes of this exclusion (Ward, 2009). Powell notes the anguish, pain, and feelings of insignificance that derive from being unheard, un-seen, discounted, and thus, unknown (2001) and the resultant un-knowing or mis-knowing: feelings and consequences clearly voiced by Robin, Bob, Sam, and Donna.

What I believe to be an important lesson, if you will, for social work is how, in opposition to demeaning yet commonly held assumptions of the (in)ability of people with intellectual disabilities, the group members' work made plain how astute and 'able' they really are. And, while I and others who share relationships with or have had more intimate experience with people with intellectual disabilities are likely not surprised by this, it is my sense it would yet prove a revelation to many in social work. The group members' insights were powerful and heartfelt, emerging from their own lives and experiences, and led to incredibly rich, emotionally and politically-charged discussions about how to change the images as a means of articulating their critique, telling different stories, challenging and disrupting taken-for-granted notions of intellectual disability, and making visible the plurality of meaning of intellectual disability. The changes were creative, insightful and powerful. What was important about these transformations was that they told radically different stories about people with disabilities. For example, rather than re-presenting powerless victims, new images portrayed strength and resistance. Pity became defiance. Abuse became revenge. Abandonment turned into a loving touch. Empowered to tell their stories visually, the transformations reflected group members' growing politicization – a politicization linked to their connecting visual representations with the social, political and economic arrangements that so significantly impacted their daily lives.

Revealed was that the group members want to be seen – but to be seen otherwise; seen as something other than what we understand them to be. In their saying 'look at me', articulated through their re-imaging and re-imagining intellectual disability, inserting themselves in the images, and staring back, they enact a visual political activism – one that not only calls into question traditional (paternalistic and maternalistic) research methodologies and social work practice with this group, and social work 'expertise', but one that quite deliberately asks us to

think differently about them as individuals (Garland Thomson, 2009) and to do, as Wendell (1996) asks us to do – to think disability (and disabled people) differently. A challenge is thus posed by the group members' to what we think we know about intellectual disability and the lives and (dis)abilities of people with intellectual disability. Neither is nearly as neatly dichotomous (able/unable, same/different, normal/abnormal, active agent of change/passive object for change, etc.) nor as 'simple' and simply 'bad' as might have been assumed. The group members reveal instead the tremendous complexity of their lives, their abilities, their perceptions, and their reception (Albrecht & Devleiger, 1999; Grant & Cadell, 2009).

Starting from a presumption of competence, my own conviction that the group members (and many people with intellectual disabilities) could – and should – participate in and contribute to ongoing dialogues and debates about cultural and self-representations, I share Grant's and Cadell's (2009:429) belief that: "The benefit of considering broader structural influences on the lives of those receiving services extends beyond social workers. Service users themselves may benefit from a shift in perspective toward structural formulations of challenges." Reflecting Freire's (1972) conscientization and empowerment practices, and nudging towards the disability movement's broader goal of emancipation from oppression (both solidly embedded in a social work social justice framework), in being enabled to respond critically and publicly through their work with public photographic images, and to engage with non-disabled others, the group moved towards relocating the source of their troubles in oppressive dis-abling structures. As they became better able to articulate how the social world defines and restricts their lives, and to identify prejudice based on disability, they became more explicitly political. This proved a shift for some of them. While social work has been much more active in this type of work with other marginalized groups, the profession's (in)attention to the politicization of people with disabilities

(in particular, intellectual disabilities, consequent to assumptions around ability) must be remedied. Articulating how this type of shift facilitates the making of new meanings of disabled people's experiences, a re-thinking of what they themselves thought they knew, Rice, Zitzelberger, Porch, & Ignagni (2009) similarly point to the benefits of supporting people with disabilities to discover, through critical engagement and dialogic exchange, their own knowledges and to build on their capacities for social action. They argue that such capacities typically already exist and may, in fact, already work for them in their own lives in ways they have not yet come to recognize. Goodley (1998), speaking specifically to the self-advocacy movement of people with intellectual disabilities, agrees and makes the additional point that practice concerned only with empowering the marginalized other can be insufficient and even paternalistic. He asserts our practices with people with intellectual disabilities should, instead, focus on "those self-empowering actions that already exist. By doing so we can support people more effectively, by listening and acting in ways that challenge those discourses that silence and disable" (p.445). Admittedly, both empowerment (for good or ill when considered in light of Goodley's critique) and a focus on strengths are fairly standard thinking for social work practice with marginalized groups, but not yet a tenet of practice that is typically, or even regularly, applied to our practice with people with intellectual disabilities. I would proffer that it should be. To do so is argued by Powell (2001) to be a sign of respect: placing expectations and making demands of people with, in this case, intellectual disabilities to engage critically with particular ideas, materials, or experiences is to acknowledge their abilities and their possible contributions. This is about more than just providing the opportunity for voice (although I do not diminish the importance of this for marginalized groups) – it moves beyond to the expectation of critical thinking and analysis, as well as engagement and debate.

This project (like the work of Rice, et al., 2009) suggests that there is benefit to and a need for facilitating opportunities for social workers to learn directly from people with intellectual disabilities (and I will attend to this in more depth in the next section), but also for creating spaces and opportunities for people with intellectual disabilities to talk to and learn from each other – to share, witness, and affirm their stories, to recognize how their stories resonate with each other. “(T)his creates movement, or new understandings of common experiences and new energy for action...[as well as recognition of] the collective knowledges and skills that are present within the group (Rice, et al., 2009:322) and can be very empowering. In their attentiveness to each others’ stories, they learn more about the broader context and, consequently, about their own experiences.

Giving Donna, Bob, Sam and Robin the opportunity, through the research project, to critically and publicly respond to disabling visual imagery, enabling them to have their voices heard and to engage with others as they challenged this imagery and put forth alternative representations and views, has proven to be very empowering, leading to a re-construction – a re-thinking – of themselves and the root of many of their challenges. The third step of the project was an important element in this growth. As noted earlier, I am unable to fully report upon this third step – the presentation of the group members’ work to three different audiences with varying degrees of knowledge and experience of intellectual disability – in this thesis. But I do wish, however briefly, to make the reader aware of the outcome for this, too, has implications for social work(ers). The group members were actively involved in the structuring of these research exhibits: in the staging and presentation of the original and transformed images; the recruitment and methods of engagement with the audiences; and acting as co-facilitators for each exhibit. The first audience (of other people with intellectual disabilities) responded with great excitement

and enthusiasm to the work; sharing their interpretations of the images and their own stories – of oppression and joy. There was a palpable feeling of ‘community’ in the room and long-term connections made between the research group members and some of the attendees. The third audience (of people admitting to limited or no understanding or experience of intellectual disability) was deeply moved. Engaging with the group in open and honest discussion (baring their own prejudices and assumptions), many were brought to tears. All admitted to this being a transformative experience and to having a new found respect for people with intellectual disabilities more generally, and the research group in particular (who treated the attendees in their disclosures of bias and prejudice, with gentleness, respect, and dignity). The second audience (comprised mainly of social workers) were silenced by the work and, in personal interviews with me later, admitted with some distress that they were not prepared for what they saw or heard. The work was unexpected, the critique unanticipated. It disrupted what they thought they knew about people with intellectual disabilities, troubling their confidence in their own social work practice. All of these audience responses to the work were instrumental in the group members’ recognition of their own voice(s) and made apparent to them the importance, power, and value of their singular and collective voices. Feeling empowered and in control, they actively and eagerly sought out ways for the work to continue.

Atkinson (2005), writing about research as social work, has found that participatory research with people with intellectual disabilities does not always come to a tidy or easy closure. This project was no exception, yet there is also a level of excitement, for me, around what has transpired since the research project officially ended. I wish, now, to outline five key activities (although there were several more) that the group participated in upon the completion of the project: forming a group; developing a website; teaching social work students; conference

presentations; and being featured in the newspaper.

Relationships (emergent and pre-existing) were strengthened by the closeness and personal nature of the work involved in the research project (Atkinson, 2005), facilitating a sense of cohesiveness among the research participants and myself. Developing critical awareness and self-advocacy skills, combined with a shared belief in the importance of the work they were doing, seemed to direct Donna, Sam, Bob and Robin to identify as a group. Formalizing this arrangement, they named themselves *The PhotoChangers*. Not diminishing the self-advocacy component of the group, it is also about friendship, closeness, and caring for each other.

Membership in the group has become very important to them and appears to serve a number of purposes. Like Rice et al., (2009), Sakamoto, Chin, Chapra, & Ricciardi (2009), note that empowerment is possible when members of a marginalised population come together to support one another by constructing family-like networks or groups. Social work research, rooted in an empowerment-oriented framework, has the potential to benefit participants beyond the duration of the project itself. As a group, *The PhotoChangers* began to more actively support and assist each other, inside and outside of group activities. Emotionally, group meetings provide a safe and protective space for members (as well as a place for some fun as humour was an important part of our gatherings). Instrumentally, they have helped each other financially and have shared information on services and community supports. Far from being passive victims (Sakamoto et al., 2009), the sense of community fostered by becoming a group provides members greater power to resist and fight against the discrimination and marginalisation they face daily – they understand this to be their task: to help and protect each other and to work together to change people's opinions about them. There is a social element to the group but it is not a social group – its purpose is much more explicitly politically motivated.

From this came the decision to create, and publicly launch, their own website as a venue for further self-advocacy: to display their project work, address important issues, showcase creative expressions, and connect with others. Here, *they* determine how they are represented – an atypical experience for people with intellectual disabilities. On the website, they are also raising issues they have identified as important to them (e.g., employment discrimination, poverty, enforced dependence). They quite clearly recognize these issues in visual representations of intellectual disability, but also have moved beyond a limited focus on social representations to address these issues more broadly. They want to use the site to invite people with and without intellectual disabilities to read these essays, learn from them, and join with them in their efforts to end the discrimination they experience.

On more than one occasion, the *PhotoChangers* have spoken to graduate level social workers at a university about their work and their lives^{xxii}. I provided information about typical graduate class expectations and activities from which they determined the structure and content of the presentations. My primary tasks were to write down and organize their ideas, work with them to revise these to their satisfaction, type the agreed-upon scripts and prepare power-point slides. At the class presentations, I introduced the project and answered questions they felt unable to answer, leaving the group members largely responsible for the bulk of the presentation. In this venue, they are able to speak directly to social work students about their experiences and expectations of social workers, service providers, the government, and society as a whole. They designed their presentation to make students aware of their daily realities (positive and negative), their abilities and needs for support, and their understanding of how they are misunderstood, denigrated, and devalued by so many. They answered questions but, perhaps more importantly, they asked questions of the students: pushing students to think about their own thinking and

practice the group members also expected a response.

The PhotoChangers regard any opportunity to teach social workers as critically important to improving the lives of people with disabilities. Keenly aware of the power differential between social workers and clients, they talk often of the role of social workers in their lives, of the power that social workers have over them and the impact of such on the supports and opportunities provided to them. They do not believe that most social workers understand them, their lives, or the impact of the ways they are treated by social workers and non-disabled people. Nor do they feel social workers value what they have to say. Teaching social workers affords them the opportunity to flip the traditional “teacher/student” relationships social workers typically impose upon interactions with marginalized clients (Sakamoto, et al., 2009:443). Transforming social work pedagogy, it allows for new kinds of learning. What is noteworthy is that these presentations took place on a university campus – a location from which people with intellectual disabilities have historically been excluded (Warren & Boxall, 2009). The group members have been doing much of their work at the university and are establishing a presence there. Robin has noted that it is because non-disabled people don’t get to know people with intellectual disabilities that they ignore or tease them, thus highlighting another useful task for social work: facilitating occasions for non-disabled people to get to know people with intellectual disabilities (in ways and spaces that break from traditional ones) in order to overcome the ignorance that perpetuates prejudice (Bogdan & Taylor, 1989).

Barnes (2004) points out the value and necessity of having people with disabilities control the dissemination of research by and about them – what is disseminated, how and to whom – to influencing what we come to understand about disability. Sam suggested *The PhotoChangers* present their work at conferences (another exclusionary site). Following discussions as to the

types of conferences best suited to their work, and the audiences they wished to reach, we identified a number to apply to. Breaking out of allocated spaces (Kuppers, 2003) once again, the group, again, disrupted the status quo; challenging assumptions about who belongs where. While often stared at, they believe themselves to have the right and the responsibility to be in these spaces – places where they could talk to people and help them to learn about intellectual disability.

To date, we have presented at local, provincial, and national^{xxiii} conferences in the fields of disability and social work. We were also invited to participate in a symposium organized by and held at a local art gallery. The process of preparing and making presentations, my role and the responsibilities of group members, were identical to those for their presentations to graduate students and, once again, placed group members in charge of representing and speaking for themselves. They are increasingly concerned to “spread the word” about their work, what they know, and what they can do. A lesson for social work research, practice, and education is that each of these opportunities to address an audience impacts both upon their sense of self and on how others perceive them: in evidence are individual empowerment, social empowerment and social change. Each positive reception to their work and words further emboldens them to speak out. Each presentation has resulted in non-disabled audience members re-evaluating people with intellectual disabilities, questioning their own assumptions.

Arguably, the most exciting thing to happen was being interviewed by a reporter for a feature story in a major newspaper. The focus of the article was the group, their work, and the necessity of self-advocacy and self-representation. As with the research project, their website, educational and conference presentations, in the interview with the reporter the group members’ connected social representation to the larger social, economic, and political forces acting upon their lives.

This repetition, the group members' consistent, persistent, and insistent attention to these issues in *all* of their work, makes imperative the need for *meaningful* inclusion of these voices in social work and social policy-making discussions.

Bob, Sam, Donna, and Robin were overwhelmed when they realized the numbers of people who would see their picture and read about their work in the newspaper. Acutely aware of the power of the media in shaping our understandings of 'others', they have come to understand that taking their message public, to a broader and more diverse audience, is a means of working towards social change (Cole & McIntyre, 2004). For *The PhotoChangers*, this task continues. Two members have left to pursue other opportunities; four new members with intellectual disabilities have come on board. We are presently nearing completion of a second research project (initiated by *The PhotoChangers*) wherein the group have identified a number of issues important to their lives – issues that emerged in their work on the first project (e.g., poverty, parenting, belonging, etc.) – and are exploring different ways to use photography to visually articulate these issues. Again, they are planning to publicly exhibit this work. At the same time, they are learning more about conducting research and thinking about other research questions and methodologies to pursue.

Make Me (re)Think Me (social work)

Arnd-Caddigan and Pozzuto write that “social work is an unfinished profession, as it should be” (2006:424). Like Rossiter (in her consideration of Levinas' ideas for social work), they see value in this; the benefit of constantly questioning the ‘rightness’ of what social work(ers) understand, do, and teach, particularly in light of the concerns expressed by Rossiter over social work as a site of “profound, repeated, and often violent historical and discursive conflicts” (2006:139). Applying this ethical and epistemological attitude to intellectual disability, can we

rely with any confidence on what it is we think we know about intellectual disability and the lives of people so labelled? Recognizing and acknowledging the absence of the voices of people with intellectual disabilities (an absence that is both made plain and confronted by the voices of Robin, Sam, Donna, and Bob) brought about by our exclusion of this group from social work theorizing, research, practice, and pedagogy, what is the response now required of social work(ers)?

To start, a radical re-thinking would seem to be in order. Deemed more consistent with goals of social justice and eradication of oppression, social work is advised to “alter its ‘frames’” (Grant & Cadell, 2009:45) and relinquish its stubborn exclusive reliance on medicalized understandings of disability, and a pathological worldview that problematizes social work clients, cements the dividing practices that separate social workers and those to whom they provide support, and the uneven power relations that result (Grant & Cadell, 2009). Calling into question taken-for-granted assumptions about intellectual disability (Fawcett, 1998), social work must adopt a critical perspective regarding disability and social work’s response to disabled people (French Gilson & DePoy, 2002). Both the literature, and the results of this project, would underscore for social work(ers) the need to take a more critical look at what (how and why) we think we know about intellectual disability and people with intellectual disabilities, to re-consider and re-make our theoretical frameworks of intellectual disability, and our understanding of our social work responsibility to people with intellectual disabilities.

As critical disability theorizing, Derrida, and Levinas would all suggest, justice demands our effort to know *but* to know differently, to think otherwise, to decentre ourselves by letting go of our (social work) ‘expertise’ (Rice et al., 2009) and opening ourselves to the Other in the spaces of research, practice, policy-making, theorizing, and teaching. It thus involves an attentiveness

to disability brought about by and through our attentiveness to people with disabilities themselves. This is not to suggest this is necessarily easy, or even a straightforward thing. It involves being available to the Other, a presencing that conveys this availability, that conveys an openness to listening and to hearing what is being said. We, as social workers, have no choice but to listen. As articulated by Simon (2004), what is required is the non-indifference of learning to listen. This is the first promise that adherence to Zakhor entails: to listen and learn. As has been reinforced by the literature, “hearing” the stories labelled persons demands that one listens differently, that we “listen otherwise” (Simon and Eppert, 1997:180), outside of that which we think we know. It requires that one adopt an embodied cognizance within which one becomes aware of, self-present to, and responsive toward someone beyond oneself – a summoned Kavannah. (Especially) when the other does not communicate in typically understood ways, we must listen with a dual attentiveness to both the *saying* and the *said*, ever conscious of how the telling, the *saying*, will always exceed the words spoken (Simon, 2004) and of how the *saying* often undoes our discursive grasp of the *said* (Simon and Eppert, 1997). As was made plain in this project, it involves both listening and hearing (to words and the emotions behind them), and also to looking and seeing (attending to embodied reactions to the work, to each other, to me): it thus requires time spent with people with intellectual disabilities, an investment of time not always consistent with contemporary forms of social work practice and research.

What cannot be understated is the idea that such an attentiveness demands, too, beginning from a position of not-knowing. Starting from a position of not-knowing, from recognition of our own un-knowing, “knowledge works have to be deconstructed and ‘facts’ recognized as transitional, privileged interpretations (Fawcett, 1998: 274). Social work’s (self-)positioning as ‘expert’, paired with dominant discourses of intellectual disability and assumptions regarding the

(in)capacities of people with intellectual disabilities, would likely appear to find such a notion disconcerting at best. What else is there to know about intellectual disability beyond (seemingly) well-established 'facts' of biology? This project would suggest that a great deal more can be known.

What is required goes beyond the deconstruction by social workers of existing knowledges of intellectual disabilities. "It is further argued that privileged, fixed positions and oppositional frameworks do not have a place; rather, the emphasis is on partnership, negotiation and collaborations, with group membership being continually open to change, re-interpretation and realignment" (Fawcett, 1998:274). This means not only listening, but also reading, asking questions, and engaging people with intellectual disabilities in discussions: learning from them, learning with them as they learn from us and from each other; and telling others what we have learned as a means of facilitating and opening spaces for more and ongoing dialogue, for new ways of thinking about intellectual disability and being with people with intellectual disabilities. This, then, involves a different type of relationship with people with intellectual disabilities – one that presumes competence and ability and is, thus, respectfully inclusive. It simultaneously moves beyond the traditional social worker/client practice dyad to include (many) others. This is the pedagogical function inherent in our listening and attentiveness to the Other (Simon & Eppert, 1997). It is a relationship of responsibility and respect imbued with the charge of justice, compassion and hope. Listening, in demanding a re-telling, informs those readers "yet to come", that what one has heard is important to remember. Fulfilling the responsibility of an "educative legacy" (Simon, 2000:11), "true learning consists in receiving the lesson so deeply that it becomes a necessity to give oneself to the other. The lesson of truth is not held in one...consciousness. It explodes toward the other" (Levinas, 1994:80, in Simon and Eppert,

1997:175). More than simply coming into new knowledge, this then becomes an ethical, political, and pedagogical practice (Simon, 2004). This effectively turns the tables, putting the onus not on people with intellectual disabilities to conform to our (misbegotten) theories, but on social work(ers) to (constantly) re-consider, re-think, re-make social work in a way that is more responsible and responsive to people with intellectual disabilities. A ‘reckoning’ is thus also required. This is enacted, not only through a recounting or taking in of the stories of people with intellectual disabilities, but by taking these stories into account (Derrida, 2001b). To *not* do this serves only to replicate and continue the violence of our ways of knowing.

This does, however, have significant implications for social work. In the case of research, for example, this reckoning makes imperative the need for more meaningful inclusion of people with intellectual disabilities – a call voiced increasingly loudly by the disability community and one which the ongoing activities of *The PhotoChangers* would seem to defend. Turning to Lather (2008:219), it would seem to behoove social work to adopt what she terms a “sense of task”, opening the social work research community to more inclusive and culturally indigenous ways of knowing. Playing with Lather’s term, “endarkened feminist epistemology” (2008:219), I invite social work researchers (and also theorists, educators, and practitioners) to take up a ‘disabled epistemology’ – to critically examine the ableist dimensions of social work knowledge practices in ways that are informed by and rooted in the understandings of disabled people. Lather suggests this is a more ethical, responsible, and accountable means of moving towards decolonizing (en-abling) research methodologies and knowledge production (2008).

The inclusion of people with intellectual disabilities in all forms of social work knowledge production (and dissemination) provides social work with an opportunity. In Levinasian terms, this is an opportunity to answer the call of the Other, to ethically respond to the address of people

with intellectual disabilities. It is, simultaneously, the chance to begin to ‘fill in the gaps’ of our knowing, to listen to the “still open wounds, scars, and hopes” of people with intellectual disabilities that can “teach us about what remains to be heard, read, thought and done” (Derrida, 2001b:118, in Lather, 2008:222).

In this project, the group members spoke quite eloquently and powerfully of the exclusion of their voices, their knowledges, their feelings, and experiences. They *do* have experience, knowledge, opinions, and feelings but *no-one has asked them* for these. And, as has been discussed, the social work and disability literatures admonish social work for having paid insufficient attention to disability more generally, and intellectual disability in its particularity. So long dependent upon an individual pathology model of disability, Grant and Cadell (2009) suggest that social work(ers) have a grossly inadequate understanding of the very real, multiple and intersecting barriers experienced by people with disabilities. Social work research and pedagogy – be they for/in policy or practice – must “make room at the table” (Lather, 2008: 220). Certainly, *The Photochangers* have proven they are ready and able to this and have made plain their belief that they have the right to be at the table. By opening ourselves to people with intellectual disabilities, we can move toward a practice of critique that is marked by disability and that is generative of approaches to research and knowledge production that are responsible to the disabled Other; “responsible to the struggle for voice, the possibilities and limits of connecting across difference, and the productivity of simultaneous tension and reparation in solidarity efforts” (Lather, 2008:228; Rice, et al., 2009).

Rice et al., (2009) suggest the insights of people with disabilities, insights rooted in lived experience, position people with disabilities as sites of knowledge for professionals and others with and without disabilities. Undoubtedly, my own experience in this project attests to this

idea. Lather notes that opening ourselves up to this expertise dislocates and positions us in a “de-authorized space”; moves us “out of commanding, controlling, mastery discourses and into a knowledge that recognizes the inevitable blind spots of our knowing” (2008:224). This would seem to have some degree of compatibility with a Levinasian understanding. Social work responsibility towards people with intellectual disabilities then is no longer established beneath the ever-shifting givens of ‘expert’ social work knowledge influenced (if not actually determined) by the contemporary gaze (i.e., dominant discourses of intellectual disability). Our social work response must be based less upon prevailing theories of the day or agency mandates than on what is required of me by the person facing me. Being-for-the-Other thus becomes a timeless vocation, a non-in-difference to the Other moving beyond the contemporaneity of social work knowing.

But, as Rossiter (2006) articulates, this is, in essence, an opposition to social work’s elemental will to knowledge, the afore-mentioned unceasing search for the Practice Answer. She notes the importance of models and forms of social work knowledge to practice. Similarly, John (1994) cites social work’s responsibility as a generator of knowledge. But we do not, perhaps, have to completely relinquish all knowledge. Returning for the moment to Levinas’ conceptualization of a justice rooted in our non-indifference to the Other, he writes that “the basis of consciousness is justice and not vice-versa....When we talk about consciousness, we are talking about knowledge: to be conscious is to know; and in order to be just it is necessary to know: to objectify, compare, judge, form concepts, generalize, etc.” (Levinas, 1998:204). The difficulty lies in assuming we can ever completely know the Other – we must remain humble in the face of the limits of our knowing. Social work with people with intellectual disabilities, undertaken from a position of not-knowing, moves us out of our comfort zone and into uncharted territory. A Levinasian

attentiveness and listening is a way of thinking (Simon & Eppert, 1997), a movement towards not only a critical learning, but also a risk-laden one (Simon, 2004). It is a listening that says “I want to learn even if, in this approach as an apprentice, I submit myself to learning the limits of myself and thus bare myself to a wounding, a trauma inflicted by this other’s story” (Simon & Eppert, 1997:179). Borrowing Benjamin’s idea of “counsel”, Simon (2004) argues that the lives of others will only truly matter if their stories (and the difficult knowledge contained within) are encountered and accepted as counsel, as having the potential to challenge and shift our own stories in ways that we neither anticipate nor easily accept. In opening ourselves up to the Other, we risk an exposure that may wound, that may necessitate not only new learning, or re-learning differently (Grant & Cadell, 2009), but also the un-learning of what we know as a means of moving in a different direction (Lather, 2008). Arguably, to do so disrupts, and/or undoes, entrenched practices. As articulated by Chambon and Irving (1999), “(t)he process of undoing is no doubt disquieting”. To be so unsettled can be upsetting, possibly even frightening for some. Grant & Cadell note, however, that it need not be: the “strengths, talents, and resources of service users are not a threat” to be resisted – instead, the combination of these strengths, talents and resources with our own creates a radical potential for change (2009:429). A study by Stainton (2002) on the responses of social workers to direct payments as a provision of governmental support to people with intellectual disabilities suggests social workers might not resist very much at all. Stainton found that, for the most part, social workers working with this population would prefer to work from a citizenship, rights, and social justice perspective, “even when it meant loss of control” (2002: 762). Indeed, with appropriate training and resources, and in a supportive structural context, social workers can be very effective allies of disabled people. Regrettably, Stainton also notes the challenges posed by competing discourses (market versus social justice) and by systems that constrain workers rather than enable them to adopt new ways

of working; obstacles that must be challenged and overcome (2002). My own experience here makes plain it is an approach to social work research that also requires the provision of time – the time to establish relationships; to address communication and other cognitive, physical, or sensory issues; the time to attend to other issues and situations that may arise. As Atkinson (2005) notes, however, such social work relations can prove enriching to all involved.

If, through being present to and sharing different social work relationships with persons labelled disabled, we adopt a new way of thinking about them, we are enabled to open up new ways to enact our responsibility and possibilities for change, for the labelled person, for the profession, and for human action.

Who we are is not only what we did, do, and will do, but also what we might have done and may do. Making up people [in this case, both people with intellectual disabilities *and* social workers] changes the space of possibilities for personhood (Hacking, 2002:107).

In other words, “(t)hings are not simply as they are, they come to be; we come to be who we are along with them” (Chambon and Irving, 1999:260). By comprehending our position-in-the-present in our acknowledgment that people labelled disabled have knowledge that we, in our ‘expert’ ignorance, have suppressed and repressed, can we not ‘set the stage’ for the ‘not yet’, for the development of new epistemologies grounded on that knowledge? Not for the unachievable ‘right way’ of practice, but for a better way of enacting our social work responsibility to the Other standing before us and demanding a response from us?

The question (and obligation) for social work(ers) may then be how to listen, to hear and map the (differently articulated) stories of labelled persons who rupture, or fail to present, the common experience of disability (ableist ideas of disability) and whose inscription of disability is, instead, done in an uncommon way (Titchkosky, 2003). It is in this way that we can use disability to

make us think by situating disability as a unique “teacher” of human alterity (within a culture committed to maintaining a singular sense of the ordinary/normal as unexamined values) as opposed to just one more object for knowledge production and consumption (Titchkosky, 2001:233).

All of this returns me to Newbury’s (1996) cautions, echoed by Lather (2008), that such an endeavour is not merely about accommodating people with intellectual disabilities in knowledge production, or by a tokenistic (but largely meaningless) inclusion. Neither is it about claiming “a ‘better’ vantage point” (Lather, 2008:228). Rather, it points to the need to create new spaces for research, spaces that acknowledge and start from the limits of our knowing, and situate research, as Lather suggests, “as ruined from the start” (2008:228). It demands a “deroutinizing methodology” (Sedgwick, 1997:3, in Lather, 2008:222), a “necessary and productive persistent troubling that keeps the normative from setting up shop” (p.223). It necessitates practices of producing different knowledges and producing knowledge differently (p.226). Remarking upon the troubled history that people with disabilities have with professionals, more meaningful inclusion gives hope that not all professionals “accept conventional accounts of difference” (Rice, et al., 2009:320). In this way social work interactions can be hopeful and potentially transformative.

For Levinas, our experience of the Other constitutes new knowledge. Each (social work) relation with the Other is then the beginning of new concepts, new thinking, new ways of being with Others (Levinas, transl. by Schmitz, 2001; Payne, 1991, Rossiter, 2006). Each relation with the Other is thus both a challenge and an opportunity: (how) to face each encounter from a position of not knowing, to be open and attentive to the intellectually disabled Other in a way(s) that ethically and respectfully takes into account their alterity and demonstrates an acceptance of

uncertainty and a willingness to a wounding that necessitates and makes possible not only new learning but which demands new thinking – about the Other, about oneself, and about social work.

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Appendices

APPENDIX A INFORMATION LETTER AND INFORMED CONSENT FORM – STEP 2



Title of Project:

Photographic Re-presentation and ‘Coming to Know’ Persons with Intellectual and/or Developmental Disabilities

Investigator:

Ann Fudge Schormans
University of Toronto, Faculty of Social Work
(416) 461-9735

Supervisor:

Adrienne Chambon, Ph.D.
University of Toronto, Faculty of Social Work
(416) 978-6314

Purpose of the Research:

I am a student completing my Ph.D. in Social Work at the University of Toronto. The goal of this study is to learn what people who have intellectual or developmental disabilities think about the way that they are represented in public photographs. For example, charity advertising, newspaper photographs, movie posters, medical photographs, service agency photographs and photographic art. I am also curious about what they think people who *don't* have disabilities learn about people *with* disabilities when they look at the photographs. I also want to learn about how they would change these photographs to show people what they think. How would they change the photographs to give people who don't have disabilities a different perspective about people with disabilities? Another important goal of this research is to show other people with disabilities, and people who don't have disabilities, the new images to see how they respond to them. In this way we can all learn from each other.

There are 2 steps in this research project:

1. In the first step, 3-5 people who have an intellectual or developmental disability will join me to form a research group. This group will look at 20 or more public photographs of people with disabilities to talk about how people with disabilities are represented. The group will then work together to change these pictures.

2. In the second step, we will present the pictures in an exhibit to 3 other groups of people. The first group will be made up of other people with intellectual or developmental disabilities. The second group will be made up of people who have a relationship with someone with an intellectual or developmental disability. For example, family members, friends, advocates, professionals, or service providers. The third group will be made up of people who don't have relationships with people with intellectual or developmental disabilities.

Each of these groups will have 4-8 people. Each group of people will have a chance to look at the photographs and then to record what they think about them. Then we will sit down with them and talk about the photographs together.

I think it is very important for social workers and other people who don't have disabilities to find out what people who do have disabilities think. It is important to get their opinion on how they are represented in photographs. By listening to what people with disabilities have to say, we will learn from them and we will, hopefully, then be better able to support them when they need it.

Invitation to Participate in the Research:

I am inviting you to participate in this research. To be eligible to participate you must:

- Be a person who has an intellectual or developmental disability
- Be 18 years of age or older
- Live in or around Toronto (for example, in Toronto, Mississauga, Scarborough, York region)
- Be willing to join a research group that will meet twice a week for 5-8 weeks. Each meeting will last from 1 ½ to 2 hours and will be video-taped
- Be willing to talk about photographs of people with disabilities
- Be willing to work with the photographs and change them
- Be willing to help prepare an exhibit of these photographs and show them to other people
- Be willing to talk about the photographs with other groups of people

If you prefer, you can also have a support person with you during the research project.

If you are eligible to participate, then you will need to attend an introduction meeting at the University of Toronto. This meeting will last about 1 hour. At this meeting you will be able to meet the other members of the research group. At this meeting we will:

- review the goals and the steps of the research project
- talk about what is involved in participating in the research – what is my role/job and what is your role/job
- review this information letter and consent form
- you will be asked to sign 2 copies of this information letter and consent form

Procedure:

If you are interested in participating, please call me at (416) 461-9735.

There are some things you need to know before you agree to participate:

1. Your participation is **voluntary**. That means that you decide if you participate, no one can make you. It also means that you can choose to leave the research group at any time. You have the right to choose not to answer questions you do not wish to answer. You can also choose not to be audio-taped or video-taped.
2. There may be some **risks** involved in participating. You might find some of the pictures or the discussion upsetting. If this happens, I will try to support you or will help you get in touch with someone who can.
3. There may be some **benefits** to participating. The research will not make services you need be more available or better. Nor will it change your life in any great way. However, it will give you the opportunity to have other people hear what you think. At our exhibit, we will show the pictures to other people and then talk about them. Also, I will be writing reports for school and journals, and presenting this research to other people at conferences. In these ways, your opinions may be heard by other people. These people might be other people with disabilities, families, researchers, academics, social workers, and other professionals. This may help them to become more knowledgeable and better understand people with disabilities. Participating in this study will also give you the opportunity to learn more about research.
4. All of the information that we collect will be kept **confidential**. The only people who will have access to it will be me, members of the research group, my supervisor, and the other people on my research committee. All the information will be kept in a locked cabinet in a locked room for safety and confidentiality. Your name will not be on any information unless you choose it to be. You might also choose to put your name, or include your own picture, in the pictures that we change. This will be your choice. You can also change your mind about this during the research. However, once the research is finished and I publish the final report (my dissertation), you will not be able to change your mind. Five years after the research is completed, I will destroy all the information.
5. This research is part of my education. In order to complete my Ph.D. I need to write about what we find when we do the research. I will write a final report (my dissertation), and also a number of smaller research papers that may be published in journals or books. I will also need to present the information at conferences. In this way, other people will learn about the results of our research. To respect your privacy, I will not use your name in these papers or presentations unless you wish me to do so.

We will all be involved in making the images that we exhibit and show to other people. Because of this, we will all negotiate or decide who owns each of the pictures. However, since this research is part of my education, we will also have to negotiate the ways in which I can use the pictures for the final report, research papers and presentations.

6. There is no cost for participating, nor will you be paid to participate.
7. You do not give up any legal rights by participating in this study.
8. If at any time, before, during, or after this study, you have any questions, please contact me or my supervisor.
 Ann Fudge Schormans (416) 461-9735 annfudgeschormans@hotmail.com
 Adrienne Chambon (416) 978-6314 a.chambon@utoronto.ca

If you have questions about your rights as a research participant, please contact Jill Parsons, Health Sciences Ethics Review Officer, Ethics Review Office, University of Toronto, at telephone 416-946-5806 or by email: jc.parsons@utoronto.ca

Dissemination of Findings:

Would you like to have a copy of the final research report? Yes No
 If so, we will send you a copy when the research has been completed.

Your Copy of the Informed Consent Form:

You are being asked to sign 2 copies of this informed consent form. You are being asked to keep one copy of this informed consent form for your own records. We will keep the other copy for our records.

Signatures:

Participant

Witness

Signature _____ Signature _____

Printed name _____ Printed name _____

Date _____ Date _____

CONSENT TO VIDEOTAPE



Title of Project:

Photographic Re-presentation and ‘Coming to Know’ Persons with Intellectual and/or Developmental Disabilities

Investigator:

Ann Fudge Schormans
University of Toronto, Faculty of Social Work
(416) 461-9735

Supervisor:

Adrienne Chambon, Ph.D.
University of Toronto, Faculty of Social Work
(416) 978-6314

Purpose of Videotaping Research Group Meetings

If you agree to participate in this research study, you will be participating in a number of meetings with me and with the other members of the research group. We will be working with many photographs and having discussions about them. There will be a lot of information as a result of this work. Because of this, I would like to video-tape the research group meetings. Video-taping the meetings will accomplish a number of different things:

- It will let us review what we did in our meetings to make sure that we do not forget important information.
- It means no-one needs to take notes in our meetings. Instead, we can concentrate on the work we are doing and the discussions we are having.
- It will let us assist members of the research group who might have difficulties with communication. We can make sure we understand what they are telling us.
- People communicate non-verbally, using body language, facial expressions, or emotions to show what they are thinking and feeling. Video-taping our meetings means that we can use both our verbal communication (our words), and our non-verbal communication to understand what people are thinking about the photographs.
- Video-taping means we can watch and listen to our discussions which will help us to think more about what we said, to build on our thoughts, and to make sure we said what we meant to say.
- Video-taping means that I have the chance to review the video-tapes to make sure that I understand what people are saying. It means I have a better chance of ‘getting it right’.
- It will provide us with a record of what we said, thought, and did with the photographs. We may choose to use some of this information when we prepare the exhibit for other people.

It is **your choice** to have the meetings video-taped. No-one can make you agree to it. We will only video-tape the meetings if all the members of the research group agree to do so. Even if only one person does not want to be video-taped, then we will not video-tape our meetings. If no-one agrees to video-taping the meetings then, as a group, we will decide on the best way to collect our information. You can also change your mind about video-taping the meetings at any time. There will be no consequences if you change your mind.

All of the video-tapes will be kept **confidential**. The only people who will have access to them will be me, members of the research group, my supervisor, and the other people on my research committee. All the video-tapes will be kept in a locked cabinet in a locked room for safety and confidentiality. They will be identified only by a code number to respect your privacy. Five years after the research is completed, I will destroy all the video-tapes.

Signatures:

Participant

Witness

Signature _____ Signature _____

Printed name _____ Printed name _____

Date _____ Date _____

PROCESS CONSENT FORM FOR PARTICIPANTS IN STEP 2



Title of Project:

Photographic Re-presentation and ‘Coming to Know’ Persons with Intellectual and/or Developmental Disabilities

Investigator:

Ann Fudge Schormans
University of Toronto, Faculty of Social Work
(416) 461-9735

Supervisor:

Adrienne Chambon, Ph.D.
University of Toronto, Faculty of Social Work
(416) 978-6314

CONSENT TO MEETING AGENDA

Date of Meeting:

Research Group Members Present

The work we have agreed to do today is as follows:

We agree that today’s meeting will be video-taped:

Yes _____ No _____

We understand that after today’s meeting, Ann Fudge Schormans will continue working with the information we collect today and with the video-tape.

Yes _____ No _____

Signatures:

Participant

Witness

Signature _____ Signature _____

Printed name _____ Printed name _____

Date _____ Date _____

Signature _____ Signature _____

Printed name _____ Printed name _____

Date _____ Date _____

Signature _____ Signature _____

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Signature _____ Signature _____

Printed name _____ Printed name _____

Date _____ Date _____

Signature _____ Signature _____

Printed name _____ Printed name _____

Date _____ Date _____

APPENDIX B

PARTICIPANT INTERVIEW GUIDE

1. When you look at this picture, what story do you tell yourself about the person (or people) with the intellectual or developmental disability*?
 - *What do you think the picture is about?*
 - *What does the picture make you think about?*
 - *How does the picture make you feel?*
 - *What do you think the picture is telling you about people with ID/DD?*

* It will be determined in the introductory meeting what term(s) people wish to use to describe their disability and these terms will be used in all discussions.

2. What stories do you think other people without disabilities might tell when they look at the picture?
 - *What do you think a person who did not have any disability would think the picture is about?*
 - *What do you think a person who did not have any disability would think about the person in the picture who does have an ID/DD?*
 - *What do you think a person with a different kind of disability would think the picture is about?*
 - *What do you think they would think about the person in the picture with an ID/DD?*
3. Are there any stories in the picture that you don't think get told?
 - *Do you think that there is another story that should get told?*
 - *Do you think there is another story hiding in the picture?*
 - *Do you think the person in the picture with an ID/DD would tell a different story?*
 - *What story do you think they might tell?*
4. When you look at this picture, what story do you think should be told about the person with the disability?
5. Who do you think decides what stories you tell?
 - *Do you decide what story you tell when you look at the picture?*
 - *Does someone else decide?*
 - *Who?*
 - *Does the person who took the picture decide?*
 - *Does the person in the picture decide?*
 - *Does someone else decide?*
 - *Does anyone or anything else influence what you see when you look at the picture?*
 - *How do you know who decides?*
6. Do you think there is any way to change this picture so that it tells the story that you want it to tell?
 - *What could you/we do to/with the picture so that it tells a different story?*

Endnotes

ⁱ In this work, I rely on Butler's use of the signifier "other" to denote the human other in its specificity, and "Other" in the Levinasian sense – to refer not only to the human other but also as a "placeholder for an infinite ethical relation" (2005:x).

ⁱⁱ DeShong (2008) tackles the question of defining/understanding 'ability' and 'disability' from a Levinasian perspective and concludes that Levinas' work is useful, not to broaden our understanding of just what is included in the term 'able' (in fact, Levinasian theory could be used this way to create a new ableism), but to articulate that what is needed is more attention to the question of, and wider margins of inclusion for, what we considered to be of value.

ⁱⁱⁱ Through a cultural transposition of Levinas philosophy to consideration of how the "face" of the Other, the face of those against whom war is waged, is admitted into public representation, Judith Butler (2004) looks at the limits and consequences of a publicly acknowledged field of appearance. Butler uses Levinas' ideas of ethical responsibility, and the face of the Other, to trouble the boundaries of what can and cannot appear within public life; the manner in which public re-presentations often efface what is, for Levinas, most human about the "face"; how being rendered 'faceless' (or a de-humanized Other) authorizes violence; and why and how "dominant forms of representation can and must be disrupted". For Butler, "(c)ertain faces must be admitted into public view, must be seen and heard for some keener sense of the value of life, all life, to take hold" (xviii). Butler's work with the question of humanization and de-humanization are important to this work and I take them up throughout this text.

^{iv} Levinas seems, as well, to challenge the traditional value accorded "rationality" by suggesting that while a person who is affirmed in his humanity (through reason and perseverance in being) can be considered a "rational" animal s/he is not a complete person. Recognition of the Other, accepting responsibility for the Other, prioritizing the Other may, in a sense, be unreasonable but it leads to a completeness and to a new understanding of "reason" as generosity versus calculation (2001a).

^v Solomon (2007) writes about this careful listening, or listening with intention, and its use in social work and regards it as essential for a caring / caretaking knowledge, for the kind of knowledge social work both uses and requires.

^{vi} Seeming to reflect this construct, McIntyre (2003), writes of the necessity of "being present" to individuals with Alzheimer's disease in a way that is independent of action, outcome, direction or agenda. Such a presencing permits a moral space for a more true, or authentic, meeting between people to occur. Understood as a responsibility, this presencing also understands the relationship to be asymmetrical (and increasingly non-reciprocal) as the dementia progresses.

^{vii} In this sense, I use Levinas' work on our ethical responsibility to the alterity of the Other as an overarching philosophical approach more than as a theoretical stance per se.

^{viii} Like Ignagni & Church (2008), I locate disability studies in a Canadian and United Kingdom context which understands disability studies to be inherently critical. This is in contrast to disability theorists in the United States: in that context critical disability studies (similar to that being discussed here) is distinguished from disability studies which is rooted in health-related disciplines and is not necessarily critical.

^{ix} While Barnes (2003) asserts that the social model was adapted, shortly after its inception, to include all impairments, including people with intellectual disabilities, my own reading in this area contradicts his assessment.

^x This debate on language has been an active and ongoing one of two major disability studies listserves (both based in North America but with global readership): the Society for Disability Studies listserve, and the Disability and Humanities listserve.

^{xi} My own position as parent, my professional and academic activities, and my advocacy and activism with people with intellectual disabilities directs me, in my daily life, to respectfully use people first language. In this dissertation, I am not completely faithful to this language as, at times, I wish to stress the disablement of people with intellectual impairments.

^{xii} One caution: while stressing the need to draw the body/impairment back into (disembodied) theorizing and activism (Frazee et al., 2006), Goodley (2001), however, warns us against an over-reliance on a sociology of the body in disability theory, for to do so risks again exclusion of people with intellectual disabilities and those with other cognitive impairments. We must not fail to recognize the genuine problems and challenges that can attach

themselves to bodies *and/or psyches* that are different from mainstream norms (Hughes, 2004; Marks, 1999; Parr & Butler, 1999; Thomas & Corker, 2002; Wendell, 1997; Yong, 2007).

^{xiii} In this context I understand Butler's use of the term 'frailty', not as implying inability or a physical fragility, but as pointing to the historical and contemporary effects of ableist power structures and construction of disability; ableist meaning-making processes that attempt to define disability and disabled people

^{xiv} I thankfully acknowledge Adrienne Chambon for this insight.

^{xv} Several other outlets emerged over the course of and beyond the project's duration and will be addressed in the concluding chapter of this thesis.

^{xvi} I had not included a service-agency produced billboard image in the project – there was no particular reason for this – but this proved regrettable as Sam, Bob, Donna and Robin all appeared to view these images (at least those from their own agencies) in a positive light, even encouraging me to consider taking the necessary steps to have my youngest daughter's image included on one. Our discussions demonstrated their wholehearted, albeit uncritical, acceptance of (and even pride in) these images, citing the positive messages they send and the positive effects on the self-esteem of the people with an intellectual disability featured in them.

^{xvii} Hearing Sam's fears (that the girl in the image will be killed) makes me shiver for this girl was the subject of a newspaper article about the murder of Tracy Latimer by her father, Robert Latimer. The girl featured in the image was selected because she was the same age and shared the same disability as Tracy Latimer – a disability that Robert Latimer argued justified his killing of her.

^{xviii} I wish to both acknowledge and thank Glen Walker for supporting the group's work and agreeing to stand-in for all those non-disabled others in positions of authority who, over the course of history, have exercised power over people with intellectual and developmental disabilities in abusive and hurtful ways. Glen, himself, has long been an advocate for people with intellectual disabilities and should not, in any way, be confused with those he is representing in this image by *The PhotoChangers*.

^{xix} For reasons of confidentiality, I am not including a copy of the full image of L. in this thesis.

^{xx} In this way, my use of these terms, seer and seen, deviates from that of Garland Thomson (2001) whose work references the non-disabled 'seer' and disabled 'seen'.

^{xxi} The reader might rightfully argue against this notion of the truth value of a photographic image yet many scholars write of both the evidence of the illusion of the photograph as 'truth' and the tenacity with which viewers continue to regard it as such (see, for example, J. Butler, 2004; Evans, 1999; Garland Thomson, 2001; Tagg, 1993).

^{xxii} Robin chose not to participate in any public discussions or have his picture posted on the website.

^{xxiii} The work was accepted at an international disability conference in another country. Unable to secure additional funding, none of the group members (all of whom rely on disability benefits as their primary source of income) were able to attend. Together we prepared a presentation which I made at the conference on their behalf.