Shildrick's monster: exploring a new approach to difference/disability[1] through collective biography

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[1] Throughout this paper we have adopted the linguistic device of joining difference with disability in this way. We cannot abandon the category 'disability' as it is still necessary for the political work that needs to be done to establish the rights of people with disabilities, we nevertheless would like to continually combine that necessity of the category, with all its essentialising dangers, with 'difference' and so flag the poststructuralist move toward emergent multiplicity that moves beyond binary thinking.

Abstract

Working with memories generated in a collective biography workshop on difference/disability and drawing in particular on Shildrick's (2002) analysis of monstrosity, this paper analyses the ambivalent processes through which difference is othered and abjected. It argues that through the process of abjection we disown for ourselves whatever qualities are being categorised as monstrous, with negative effects not just on the other, but also on the self. We look at the ambivalence of 'reclaiming the monster'. The paper opens up an alternative of expanding the possibilities of being by focusing not on difference as categorical otherness, but rather difference as movement, as differenciation, or becoming.

Introduction

People who are categorised as different/disabled, and their families, frequently encounter rejection in education settings, in workplaces, and in other social spaces. Sometimes the rejection is subtle and sometimes less subtle. Perhaps even more oppressive than those overt rejections, are the workings of power that are illegible. Those illegible workings of power, as Butler points out, are generally not something anyone consciously chooses; indeed their power in part lies in their illegibility: the 'normative exercise of power is rarely acknowledged as an operation of power at all. Indeed we may classify it among the most implicit forms of power, one that works through its illegibility' (Butler 1997, 134). 'Compulsory able-bodiedness' for example, 'functions by covering over, with the appearance of choice, a system in which there actually is no choice' (McRuer 2006, 8).

Neoliberal discourses and practices have created a pervasive form of governmentality through which individuals are no longer social beings but economic beings. Implicitly, in what has become ordinary everyday discourse and practice, you have no value if you are not economically productive; or to put it another way, any form of value, other than the economic, has become more or less unimaginable. That shift in which human subjects have been transformed into *homo economicus* has taken place without anyone necessarily noticing that what is taken to be common-sense in everyday thinking and practice has changed, leading to automatic exclusions of those who are not able to be seen as potentially (economically) productive (Davies and Bansel 2007; Morissens et al 2007).

Not being aware of how discourses work on you and through you does not, however, let you off the hook of ethical responsibility. In this paper we ask, with Barad (2007 x), if we are interested in justice how we are to 'understand our role in helping constitute who and what come to matter?' Justice entails, Barad argues:

> the ongoing practice of being open and alive to each meeting, each intra-action, so that we might use our ability to respond, our responsibility, to help awaken, to breathe life into ever new possibilities for living justly. The world and its possibilities for becoming are remade in each meeting. How then shall

we understand our role in helping constitute who and what come to matter?
(Barad 2007, x)

Not being aware of how exclusions matter in the lives of those categorised and perceived to be different/disabled does not absolve anyone of responsibility. In this study of encounters with difference/disability, or what Shildrick provocatively refers to as monstrosity, we explore the processes through which difference/disability is made to matter in order to 'breathe life into ever new possibilities for living justly' (Barad 2007, x).

Embodying the monster

To analyse the processes through which disability is othered and abjected, we draw on Shildrick's (2002) theorizing of *monstrosity*. At first the naming of difference/disability as monstrosity seemed quite shocking to us, but with it Shildrick provides a fascinating insight into the way that the onto-epistemological construction of normalised identities involves the normalised subject in abjecting difference/disability. Shildrick invites those who identify themselves as normal, not only to make visible the processes whereby they *abject* the so-called monstrous other, but to find, as well, ways to *re-claim* that monstrosity as *integral to their own humanity*.

The 'abject' is the term Kristeva uses 'for all those things which a subject must disavow in the attempt to secure the self's clean and proper body' (Kristeva 1982, 71). The monstrous other is abjected in the ongoing project of making the normalised self into an identity that can be recognised as normal--through which, in Shildrick's terms, we create an illusion of being both normal and distinct from others. This process she argues requires the construction of boundaries that are necessarily leaky, and that require constant defence (Shildrick 2002). She questions that process of abjection, not by following the more usual moralising argument that we *should* see the abjected ones more positively, but by understanding the complex relationality through which our humanity is accomplished: 'The issue is not one of revaluing differently embodied others, but of rethinking the nature of embodiment itself' (Shildrick 2002, 2). She invites normalised subjects to examine their fears in

encounters with difference, fears based on the use of monstrous others, and the abjection of them, to shore up a sense of their own normality.

The challenge we set ourselves in this paper was to examine our own normalising identity-making, in all its ambivalent complexity. Through working with our own memories in a collective biography workshop we opened up the possibility of exploring our own co-implication in the entangled onto-epistemological processes of normalisation and thus also of abjection. Our project is not one of normalising and condoning abjection through finding it in our own everyday practices, but of making the workings of power legible and thus open to deconstruction. In place of abjection we seek openness to the encounter with difference that enlarges what it is to be human. It enlarges our humanity. Our project is one of opening up to the ways 'we are different and multiple in ourselves' (Gregoriou 2001, 146). We circled around this project in several collective biographies (Davies et al, 2013, De Schauwer et al, 2016, De Schauwer et al, forthcoming) and our engagement with poststructural and new materialist theories.

The hegemony of normativity

In the work with people categorised as different/disabled that several of the authors of this paper engage in as part of their everyday work, we observe dismissal, a profound lack of information, and often focus on treatment and rehabilitation. This is only possible if those who are categorised as different are regarded as less than human—or at the very least as existing outside humanity as we understand it (Goodley & Runswick Cole 2014). These everyday encounters can be understood as a manifestation of ableism—of the common-sense assumption that an able-bodied/able-minded identity is what anybody would want (McRuer 2006). Ableism is a set of discourses and practices through which anyone who does not accomplish that able body/able mind is pathologised (Campbell 2009). At the same time, Bolt (2014) argues that the metanarrative of disability itself is integral to the production of normativity.

It is a complex illegible entanglement of taken-for-granted discourses and practices that we hope to go some way to making more legible through our work with

memories generated in our collective biography workshop.

It is through what Shildrick calls the ruse of identity-making that normative subjects become what they ought to be according to the subject positions that are available. Butler argues that this ruse is linked to the desire for recognition:

> 'Our very sense of personhood is linked to the desire for recognition, and that desire places us outside ourselves, in a realm of social norms that we do not fully choose, but that provide the horizon and the resource for any sense of choice that we may have' (Butler 2004, 33).

In taking up those terms of recognition, normalised subjects take on 'bodily configurations' along with the 'cultural capital they assume', enabling themselves to 'step into a position of authority and wield the power it grants them' (Garland-Thomson 1997, 8). Normativity is thus intricately linked with the working of power and 'is less a condition of human nature than it is a feature of a certain kind of society' (Davis 1995, 14).

As researchers, and as workers in the field of disability studies, we did not want to set ourselves above the ruse of identity or outside the processes of normalisation. Although we see their dire effects in our everyday work life, our best chance of making it legible, we decided, was to use the strategies of collective biography to look at these processes from inside themselves. This is not to condone them because we too do them, but to take up a position of responsibility by examining more closely how 'the world and its possibilities for becoming are remade in each meeting' and to ask how we might better 'understand our role in helping constitute who and what come to matter? (Barad 2007, x). To get inside those processes is no simple matter. In ways that are not legible to us, as McRuer (2006, 151) points out:

> The institutions in our culture (…) work to secure an able-bodied identity. Fundamentally structured in ways that limit access for people with disabilities, such institutions perpetuate able-bodied hegemony, figuratively and literally constructing a world that always and everywhere privileges very narrow (and ever-narrowing) conceptions of ability.

Despite our own commitment to working otherwise in the practical and political work in our everyday lives we are not immune from being positioned within able-bodied/able minded hegemony. We are in this sense well positioned to examine its workings in our own encounters with difference. Like Bolt we understand that despite our best intentions the language we use may be 'institutionally ableist, from the etymology to the most sophisticated of metaphorical applications' (Bolt 2014, 16). Our passionate commitment to activist work, deterritorializing ableist discourse, forms one rhizome (to take up a Deleuzian metaphor) and everyday ableist thought and practice, reterritorializes thought, in a quite separate rhizome. These rhizomes in some ways are entirely different and separate from each other and in other ways together they form a new rhizome. Deleuze and Guattari (1987, 10) ask: 'How could movements of deterritorialization and processes of reterritorialization not be relative, always connected, caught up in one another?' Working at the interface of these entangled rhizomes is vital in understanding how difference/disability is practiced:

> The rhizomatic model of disability produces an abundance of meanings that do not juxtapose pain and pleasure or pride and shame, but allow for an imminent transformation, a coming into being of a state of life in this world, one that is constantly shifting and productive of new subject/individual positions. This rhizomatic model of disability is only useful when used. It cannot have truth status, for it is empty of specific meaning. It is a movement rather than a definition (Kuppers 2009, 223).

Methodology of collective biography

The five authors of this paper gathered together for four days in a rented house in Chicago in May 2013. We had read, in preparation, Shildrick's (2002) *Embodying the Monster. Encounters with the Vulnerable Self*, and we had looked for children's stories about monsters that might open up different ways of thinking about monstrosity. Inspired by Shildrick's work and by the children's stories that we read together, we worked on our own encounters with monstrosity. Our days were spent at first sitting on the roof terrace under the Chicago sun, telling our memories of those encounters.

We listened to each other's stories in order to know them, in a Deleuzian sense, from *inside* themselves, not as individuals but in terms of the mode of being the memories unfolded. As Wyatt et al., (2011, 3-4) explain:

> Deleuze does not deny the existence of individuals and their experience; they are ontologically real. But their engagement in being, in univocal being, in all its complexity and divergence, opens up not the usual question who are you in particular (what is your identity that I might judge you and thereby judge myself), but *how is this possible?* Deleuze asks, in relation to experience, "how is that possible? How is this possible in an internal way? [Engaging with someone's experience] you relate the thing or the statement to the mode of existence that it implies, that it envelops in itself. How must it be in order to say that? Which manner of Being does this imply?" (Deleuze, 1980: np). How might I comprehend Being in new ways through listening to you inside the fold of your experience.

In order to listen in this way we questioned each other closely to ensure that we grasped for ourselves what it was to be embodied inside each of the memory stories that were told, then we wrote our stories, and read them out loud to each other, again listening in order to know the embodied moment – entering the space of each story not just as an epistemological event, but also, in Barad's (2007) terms, as an ontological and ethical event. In the telling and the writing of our memories we sought language that would ring true to the time and space and people in the memory. We sought to write in an embodied way, not resorting to clichés or explanations and not engaging in moral judgment (Davies and Gannon 2006 & 2009), but opening up the fold of experience from inside itself.

The memory stories generated in collective biography workshops are thus not objects of reflection that pre-exist their telling. They are mobile, and the work with them is *diffractive*; the stories affect each other, and we (singular and plural) affected them and they affected us, and affected and who we took ourselves to be (Davies and Gannon 2013). In arguing for a diffractive methodology Barad suggests that

reflexivity is not adequate to capture the emergent intra-corporeal multiplicities of life (Fritsch 2015). We need the concept of diffraction, she says, to open ourselves up to the ways in which difference is not something that can be fixed in already-known categories, but is a process of ongoing differenciation or becoming: 'Diffraction involves reading insights through one another in ways that help illuminate differences *as they emerge*: how different differences get made, what gets excluded, and how these exclusions matter' (Barad 2007, 30, our emphasis).

After our days of storytelling/writing/reading/listening/questioning we went back to our computers to rewrite our stories, editing out any remnants or clichés or explanations or moral judgement, or words that evoked the present day narrator rather than the person in the memory at the time and place of that memory. Further, we generated 'after-thoughts' or diffractive readings of our stories we had told and listened to, as well as the discussions of each story, and the conceptual possibilities opened up in our readings. The process we engaged in opened up from inside themselves those folds of experience that made Being visible, audible, palpable, not in the sense of capture and holding it still in order to examine it, but opening it to change:

> The discursive and material practice of collective biography can make visible, palpable, hearable, the constitutive effects of dominant discourses. (…) In examining how discourse and practice work on us, we open both ourselves and discourse to the possibility of change. (Davies & Gannon 2006, 5)

The after-thoughts were brought together with the stories after the workshop as the collaborative writing process on this and other papers went on over many ensuing months. Each of us took turns to write and re-write this paper and with each re-writing further shifts in thought were accomplished. Each contribution enabled us to work further on our collective emergent understanding as we re-configured our understanding of our entanglement in processes of normalisation and our encounters with monstrosity.

Memory stories of monstrosity

In what follows we tell three of our memory stories, which were triggered by the question: "What is your (first) memory on an encounter with a monster?" The three stories we have chosen to explore, successively, are about the processes of abjecting the monster, the ambivalent process of reclaiming the monster, and the powerful impact of embracing difference in an affirmative way.

Our first story is told from the point of view of a nine-year-old child:

> *In the days after the King's death all the news on radio and television focuses on the unexpected death. Extra editions of journals are published. One of the front pages is filled with the dead body of Boudewijn lying in his coffin. The Belgian tricoulour flag covers his legs. A white, almost transparent veil, covers his face. Or tries to cover. I say try because – at the first and only glance – I see a clear face. Not the face of King Boudewijn anymore. Not that gentle face of the King anymore. The face he listened with. No glasses anymore. A pale face with eyes closed and mouth shut. I shiver, feeling intensely frightened. I have never seen a dead body. I quickly turn the page. I do not want to see it again. It is too spooky. At the same time I have to prevent myself from turning the page back.*

> *That night it is difficult to fall asleep. The image of the dead King constantly recurs. Finally, I fall asleep, but even in my nightmare, the body appears. Even closer than I could ever imagine. King Boudewijn lies in the dark brown closet in our hallway! I wake up clammy. I have to persuade myself to get up. My legs are heavy. I am full of fear. I walk into the hallway. Unsteady. I see the dark brown closet and immediately turn my head away. The closet is big, the hallway is narrow, the space in between is too tight to pass. I will go the other way, it is the only solution.*

With this story we want to focus on the process of 'monstering' -- how multi-layered it is, and how unbelievably quickly it can come to dominate thoughts and actions like the instant decompression of a spring. For the storyteller, as a nine-year-old girl, the dead face behind the veil became the monster who lay on the other side of life, whose death must be abjected from her own body. The paleness, the sealed eyes and almost frozen mouth were intensely vivid. The picture of the dead body held more

than the picture itself: 'What is monstrous is most often the form of ... embodiment' (Shildrick 2002, 9).

The girl's response to what she experienced as monstrous involved, in Shildrick's terms, a re-establishing and maintenance of her own (normalized) body by expelling and locking out the monster. That normalized self, Shildrick argues, is doubly vulnerable:

> As postmodernist theory makes clear, the normative construct of the self's clean and proper body is under constant threat, on the one hand from the potential of internal leakage and loss of form, and on the other, from the circulation of all those dangerous bodies – of women, or racial others, of the sick, of the monstrous – who occupy the place of the other and serve to define by difference the self's own parameters. (Shildrick 2002, 71)

The girl was deeply afraid of the monster with its power to escape from the place in which she had confined it. Her dangerously leaky borders had to be protected and maintained. Monstering the other is work done at the expense of others who are monstered, but also at the expense of oneself. Placing the image of the dead king outside the self, and containing it there, required constant effort to maintain its position on the outside, like the effort required to keep a spring taut in order to hold back the instant moment of release and decompression:

> In seeking confirmation of our own secure subjecthood in what we are not, what we see mirrored in the monster are the leaks and flows, the vulnerabilities in our own embodied being. Monsters, then, are deeply disturbing; neither good nor evil, inside nor outside, not self or other. (Shildrick 2002, 4)

For the girl the dead body was monstrous, invoking at the same time horror (turning over the page) but also fascination (the desire to turn the page back). Death, now potentially her own body's death, presents her with unbearable knowledge. She was vulnerable to the knowledge of her own mortality, but she placed that vulnerability, in an instant, in the body of the monstrous other who could be locked away, but who

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continues, even into adulthood, to make her afraid: 'We thus cannot finally locate the monster as wholly other. It always claims us, touches us and implicates us in its own becoming' (Shildrick 2002, 6).

This first memory-story worked powerfully on us, enabling us to catch, vividly, the moment of abjection; a moment not wilfully chosen, nor even ignorantly enacted, but a visceral recoil from the similarity between the girl's own body and that of the deceased king. The finite mortality of all humans materialised in the image of the king was too much for the child and evoked profound fear. According to Hobbes (as cited in Frost 2010, 158) fear is 'a response to the limits of epistemology, (…) a response to the obscurity of the unknown'. For the girl, the unknown, or not-yet-known, was the appearance of, and first confrontation with, death and dead bodies. The fear evoked by the picture/the monster could thus also be read as the unbearable realisation that everyone can lose command of her or his body. The fact that the monster comes so close (from his coffin in Brussels to her home) and invades her personal space, disrupts the girl's illusion of being invulnerable.

In this interpretation the awareness of being vulnerable to and touched by death opens up a momentary recognition of the impossibility of self-sovereignty, an awareness that evokes fear, and necessitates a violent abjection of the image in order to protect her illusion of able-bodied integrity. The monstrous body must be turned into the 'absolute other' so it can, in its corporeal difference, be put 'into an oppositional category of not me' (Shildrick 2002, 2). This response is integral to the process of abjection that we set out to explore—the process whereby the binary divisions between self-with-integrity and the monstrous other are set up.

The nine-year-old girl found a very specific means of abjecting the King—locking him away in the closet. The dead body was thus made to represent much more than itself. Locked in the closet it could come to hold all the taboo elements of the self that must be separated off. What the encounter with the image of the dead body opens up for us here, with the help of Shildrick's theorizing, is the possibility of understanding that the act of abjection does not happen because the other is different, but because they are the same. Individuals' identity-making is a process of

undoing that confusion and lack of singularity. That is, in a sense, identity-making's task. It fabricates certainty out of uncertainty, and thus wards off the possibility of annihilation. Locking the King up, abjecting him, was, however, no final solution, as the fear of death is now laid down affectively in ways the girl-now-a-woman cannot readily undo. The dark brown closet in which the dead body was locked, still evokes a wry feeling of fear.

In our next memory-story another child encounters the horrifying image of her dead sister. First, alone, and then with the help of her father, the little girl finds a means of managing the horror and embracing, within her family, the memory of her dead sister. This story thus enables us to extend the analysis we undertook with the first story. This time the memory is literally taken out of the cupboard.

> *When I come into my playroom I see the old heavy brown safe. It's big with a code system with numbers and letters and a special key. It's always closed but today the door is open. I feel excited, maybe there is some money in it, that I could use for my chocolate shop. I look behind me to make sure that my sister didn't follow me. On one of the shelves I see a white book bound in plastic. I open the book and I know it. It's a book about Catherine, my sister who died. The only thing I know about her is that she only lived for a week. I turn the pages and there I see a picture: a little cradle with a body in it. A very small body. Out of her mouth comes a tube; there are wires and tubes all over her body. I feel shocked and I put my hand before my eyes, like I do if I see the Hulk on television, especially the moment were his body changes from a person into a green monster. After a moment I spread my fingers a little bit, so I can see something. It are all black and white photos. It looks like you can see through her skin. Was it soft? Would she cry? Could she play in my chocolate shop? I look again at her face and if I look closely I can see a cleft chin… like mine… I turn the pages. The last picture is the baby with my mother. My mother holds her, no tubes, no wires. Just my mum with the baby.*

> *At that moment I feel somebody is standing behind me. I don't move. It's my dad. I*

feel him going down on his knees and he touches my shoulder. He takes the book and gently closes it. He puts it into the safe and turns the switch. He closes the door with the special key and puts it in his pocket. He stands still for a moment, with his back to me. Is he crying? Is he angry? What is he thinking? There is silence.

I say: "Catherine with a C is a nice name." After a while he says "Yes it is, it comes from Catharina, just like your sisters, but you also have a lovely name".

Catherine is the third daughter in this family, who only lived for one week. She is locked away in the safe. She is not mentioned, and yet the family silently circulates around her absent presence. On one hand, there is apparently no place and space for her, no pictures in the house, no stories told from the pregnancy, the birth and the short life. At the same time the pictures of the baby are put in the most secure place, a place that both hides her *and* underlines her significance. In the moment of discovering the photos, Catherine's life is ambiguous, far away, invisible, but close enough, with no escaping. Monstrosity, Shildrick says, 'arouses always the contradictory responses of denial *and* recognition, disgust *and* empathy, exclusion *and* identification' (Shildrick 2002, 17).

When the girl sees the pictures of the unrecognizable corporeality, she hides from the image. This baby does not conform to what a baby *should* look like. The process of identity-making, as the girl has experienced it, produces normality. Now she is confronted with an image that refuses that process—that is, in Shildrick's terms, monstrous. And monsters 'are always liminal, refusing to stay in place, transgressive and transformative. They disrupt both internal and external order, and overturn the distinctions that set out the limits of the human subject' (Shildrick 2002, 4). The safe, the knowable and the known are interrupted, disrupted. That disruption generates ambivalent emotions. The girl peeps through her fingers, and her horror alternates with desire—might this sister have played in her chocolate shop? If this child, this sister, is too threatening to the girl's own boundaries, she might cast her away as someone who cannot be and should not be worthy of her attention. As Shildrick says: 'What is at stake in a politics of identity and difference is the security

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of borders that mark out the places which are safe and which are unsafe, and who is due moral consideration and who is not' (Shildrick 2002, 5).

But the girl has discovered in her sister a point of sameness: she shares her cleft chin. In that discovery she experiences not simply otherness, but what Shildrick calls 'the trace of the other in the self' (Shildrick 2002, 129). The monster is thus a figure of ambiguity. 'It is not just abhorrent, it's also enticing, a figure that calls to us, that invites recognition' (Shildrick 2002, 5). And so for the girl, her moment of discovery holds all the ambivalence the world had for this baby when she was born. Rejection *and* recognition.

In the playroom something shifts in the space between the father and the girl. The father doesn't judge the girl for looking at the book. He is really gentle with her and with Catherine. He touches the girl's shoulder and takes the book from her with great care. The moment he closes the door of the safe and stays with his back turned to her, something new opens up. When the girl cannot see what her father is doing in this moment of silence, she wants reassurance, a return to normality. And in that same moment, everything changes in the face of her father's vulnerability. His body holds his grief; his back is turned, and he is silent; and within that silence the girl feels what the loss of her sister has meant to her family.

The girl had felt her own vulnerability looking at the pictures of her fragile sister, and she feels the powerlessness and gentle sadness of her father. His body shows the loss, his turned back, his silence. This is also a moment of humanising Catherine. She is not a scary object in a picture any more, not the daughter without a face. She is someone you can be sad for, about whom you can grieve. Catherine is not the monster outside the girl any more, she touches and is touched by the girl, two girls with a beautiful name. She experiences now, as an adult, in the telling of this story, the 'ambiguity and unpredictability of an openness towards the monstrous other [and comes to know] both vulnerability of the other, and vulnerability of the self' (Shildrick 2002, 3). She comes to know her sister as integral to her own life, even in the deep sorrow of her loss.

When we listened to this story, we were all touched, not just by the loss, but by the

detailed account of love for that child who lived so briefly. As we followed the story, and listened, we became witnesses to the intensity of love and respect for another human being. Each member of the family, including the child who lived and the child who died, and their father, go on affecting each other, transforming each other, and they potentially transform those who listen to their story. Catherine is no longer someone to be abjected, no longer someone not granted humanity, but someone granted a viable place in the heart of the family. Who any of us are, or might ever have been, is never absolutely fixed. We are each, as Shildrick says, historical works in progress.

At the time of this encounter with her sister, her father's sadness *affected* the girl and humanised her. It touched her in a way that had, and goes on having, implications for her own becoming, for the desire that has become a driving force in her life. In that world, Catherine is much more than a body that inhabits the categories of 'spina bifida', 'severely disabled', and 'unviable'. The girl and her father are, through their shared affect, their shared desire, touched by and connected with Catherine as are we, now, in the process of engaging in this collective biography: 'Desire produces connections and creates belonging (…) belonging in constant movement' (Diedrich 2005, 242-243).

We are aware here of a danger that Catherine's life will be read as valuable for *our* sakes, for the sake of *our* able-bodied humanity. And while it is true that her life, and the memory of it as it is told here, do contribute to our sense of humanity, that is not our point. Our point is that life itself is mobile and intra-active. Despite all our efforts to establish ourselves as stable and separate entities, we are mutually entangled in our encounters with each other. Barad generated the neologism 'intra-action' to help her explore the ongoing '*mutual constitution of entangled agencies*'; 'intra-action recognizes that distinct agencies do not precede, but rather emerge through, their intra-action' (Barad 2007, 33; emphasis in original). In that openness we come to understand that the binary abled/disabled is deeply problematic; none of us exists absolutely on one or the other side of it (Goodley & Roets 2008), and none of us exists independent of our intra-actions with the other.

The plenitude that circulated around Catherine, once her presence was acknowledged, was most vivid in the way the parents raised their other daughters. Catherine brought them positivity—a capacity to joyfully embrace life. Her story thus contained much more than a melancholic sense of loss; in acknowledging her the family opened itself to difference, not just Catherine's different life, but their own humanity lived differently. In embracing difference, one's own humanity is expanded and intensified (Davies 2014).

The story-teller's clearest childhood memory is the annual visit to Catherine's grave each first of November, the father with his cleaning products and the girl helping, scrubbing and cleaning. After that they would go together to drink warm chocolate. The desire to include Catherine in this family is in Olsson's terms 'an unconscious process of production: it concerns a kind of learning that it is not possible to tame, predict, supervise, control and evaluate according to already existing standards' (Olsson 2009, 185). It enables the family to discover new connections and possibilities, to construct and reconstruct themselves and their world over and over.

In our third memory the daughter lives, and her sister tells a story about daily life with her. This is a story of a family with a mission, a constant battle and an obligation to de-monster their severely disabled daughter for themselves and for the world. Their experience of intense contact with the child, means that however disabled or malformed she may appear, she is a unique and irreplaceable being, and above all a member of their family.

> *I look at the ticking clock in our living room. It is 2 minutes before 10 pm. I lie in the dark watching a movie. My parents are already sleeping, but I'm almost 14 and old enough to stay downstairs on my own. Actually, not alone. My sister, Margo, who is four is lying in her bed in our living room, sleeping, I think. The clock beats 10 times. I stand up and go to the kitchen. I prepare for the injection of medication, 2 milligrams of Depakine. I put on the big light to see what I'm doing. My sister opens her eyes and makes them big. She forms a sound, saying 'euh' with a big smile on her face. And again, 'euh'… I smile and look at her, my*

heart feels warm. She knows I will give her the medication. 'Ah, Margo, I thought
you were already asleep, because you were so quiet, but you sneakily were
awake.' Her eyes stay big and I smile again. I stop the machine that gives drops of
liquid food and carefully inject the medicine very slowly into the tube. I do it as it
should be done and almost automatically. It is not the first time. I look at my
sister with that attentive look in her eyes. She trusts me with this task. I'm her big
sister. At that moment my heart goes faster and for a second I'm thinking: 'What
am I doing here? My friends do other things with their brothers and sisters,
teaching them to do math sums for example. I would like to do that also.' My
heart goes fast and I'm shaking a little bit. How do I dare to think like that? Then
I start the machine with food again. I turn down the light so she can go to sleep
and give her a kiss. Her hair smells nice and fruity. She says 'euh' again and
smiles. Her body is relaxed, ready to go to sleep. I smile back with tears in my
eyes. I go back to the couch to watch the end of the movie.

In this memory-story we meet two girls in a familiar intra-action as sisters, enjoying each other's company and feeling a strong connection. At the same moment one of them has to perform in a way that is not usually expected of a girl of her age. When she gives the injection, she acts like a caregiver, and a nurse. She catches herself wanting to do other things with Margo: playing, running in the streets, teaching her maths... Her relationship with her sister holds this ambivalence. The girl loves her sister and is sensitive to her eyes, her smell, her touch, her body and her moods. This attitude and activity is under-pinned by desire, uncertainty, interests, and it leads to questions instead of answers. Her sister confronts her with impossible hopes and strong emotions about what is not. She is startled by her own ambivalence, by her momentary slippage in this collective biography process into thinking of Margo in terms of what she is not.

Isarin (2005) distinguishes between the 'who' and the 'what' of the child. The 'what' categorizes the child in terms of 'everything that is not expected, not planned, not hoped and not wished' (Isarin 2005, 6). It is an absence, an overwhelming negativity. A member of Margo's family captured the perception of the *what* of Margo when he

said at her funeral: 'It is a good thing, for her and for you. Now she is in heaven and she is released from her impairments and sorrows. In heaven she can be whoever she wants to be. Her body can be released from pain and deformity.' But *who* is Margo? 'The 'who' is the subjective singularity of the child. It is the person, regardless, or just because of, his or her disability. The 'who' is through and through relational; it can only be recognized and acknowledged in relation with the person' (Isarin 2005, 6). In Barad's and Fritsch's terms, the 'who' is intra-active, it is an emergent, intra-corporeal, multiplicity, a mutual entanglement.

The well-meaning words at the funeral unintentionally denied the mutual entanglement the parents and sister had with Margo, and the world they had created with her, of inter-connected bodies and souls. The words denied the hard work the family had put into the de-monstering of Margo and the de-monstering of themselves as a family, and they rendered invisible, even impossible, the work of breaking out of those binary 'categories that block the unfolding of new ways of living' (Lorraine 2008, 72).

In this story the family works with the potentialities of the child and engages in an on-going battle against ableism and its binary categories and processes of abjection that reduce Margo to a unit of lesser value (Hannah & Midlarksy 2005). They defend the 'who' of Margo, and they get to know every loving detail of her, her laugh, her big eyes, her patient way of living, her moments of enjoyment, her recognition of them as family. The words of their well-meaning pious relative were wounding in their abjection of Margo as monstrous; they flew in the face of all their hard work to de-monster her, to remain open to her sameness in all of its difference.

When Margo had stayed more often in the residential care facility for children and adults with severe and multiple impairments, her father had visited her every day. He walked with her, talked to her about her family and their daily life, went to the cafeteria with her for a drink, gave her a massage, read his newspaper next to her, held her hand. They were very close. He had had to work hard to make his humanising of Margo make sense to the professional staff who took care of her. There were many discussions about what was best for Margo. The confrontation

with otherness demanded a different becoming as it challenged the pre-existing order of what a child *should* be. It demanded movement from an unreflected *ought*, to what *is*, and thus a movement away from moralistic judgement toward an ethical openness to the just-thisness of Margo.

Concluding thoughts

We launched ourselves into our collective biography workshop, as five works in progress, five people committed to finding new insights into the way normative anxieties work on us and through us. We were five people who did not 'believe in' abjecting others, but who came to understand, that, like *anyone else*, we both succumb to *and* struggle against the forces of normalisation. We have explored difference as movement rather than something that can be categorised; and difference as a positivity that lies beyond or in-between binary differences of same/other, abled/disabled. We have explored the possibility of thinking of difference as emergent in mutually constitutive entanglements, or differenciation. We have questioned the normalising ideal of a stable identity and called for engagement in an ethics of openness to what is rather than what ought to be. What if, we have asked, we put the spotlight on our intra-active encounters instead of on disability?

The dynamic we explore here, inspired by Shildrick's analysis, is deeply personal, working on and through individual bodies and emotions; it also works at the level of epistemologies, moralities and affects. We ask not just what is it to be this singular being, in this moment of abjecting or being abjected, but what kind of a world are we making in that moment? When we abject the other, we refuse for ourselves the possibility of knowing the richness of the other, and we repress the otherness within ourselves.

This is not a paper that dismisses those who fear and abject those who are labelled as 'different'. It is a paper that enters into the micro-movements of that space of abjection in order to make abjection visible and all-too-human. At the same time it argues that abjection is a burden to the one who holds the abjected other at its borders. Through the collective biography we experienced these processes at work

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on all of us, creating our own ambivalent relation to those categorized as other and as monsters. Our task here has been to gain some conceptual purchase on the processes of abjection and to set out moments of conceptualizing 'difference' in an alternative, more fluid way, inspired in particular by the conceptual field that Shildrick has opened up.

The methodology of the collective biography helps us in making 'visible and revisable the everyday discourses through which we make meanings and selves' (Davies & Gannon 2006, 7) and in particular, here, the making of identity and otherness. Before we began this project we had imagined that we were immune to the process of abjection of difference/disability; in thinking of ourselves in that way we had created yet another binary of right-minded people like us, as opposed to those (monstrous) others who treat difference/disability as monstrous. Working with Shildrick we re-claimed the monstrous other we had created through this moralising binary that placed us in the dominant position; we looked to ourselves to discover from inside itself how the process of abjection works on us and through us. We explored through Barad's and Deleuze's thinking about justice and ethics a non-moralistic, non-judgmental approach. Through our collective biography processes, and through our engagement with Shildrick's theorizing, we have opened up the possibility of an ethics that does not judge ourselves or the other, but asks, simply, with Deleuze (1980), *what is it to be this*? We hope we have shown in this paper what a profound and productive question that is.

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