

Putting Us Away: Excavating Two Journeys to Find Alternatives to Community Living. A Review of *The Boy In The Moon* (2007), by Ian Brown, & *Her Name Is Sabine* (2007), by Sandrine Bonnaire

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"...[the] capacities, needs and behaviours of persons, and their past and future hopes, can be seen in very different ways depending on who is producing the story about the person... and very different consequences can result depending on whose story is given recognition."

—(Bach, 1994, p. 143)

"You have immortalized Walker in a way few of us ever will be..."

—(Monika, 2007: http://www.theglobeandmail.com/servlet/story/RTGAM.20071130.wwalker_comments/CommentStory/lifeFamily/home#comment1522696)

"Let's say it out loud; Her Name is Sabine is the most beautiful film that Cannes has given us this year."

—(Roy, 2007: http://www.fipresci.org/festivals/archive/2007/cannes/cannes_her_name_is_sabine.htm)

We live in what Rosemary Garland-Thomson (1997) calls an "image-saturated culture," where widespread and commanding images of disability have great potential for shaping public consciousness and perpetuating the notions, among others, that disability is synonymous with illness and suffering and that disabled persons are incapable of fully participating in community life (Barnes, 1992). In the past 25 years, mainstream media (ranging from coverage of the Paralympics, films with disabled characters, press and tabloid coverage about "crazy" movie stars, and medical miracles) has served to bring disability out of the closet and into the public sphere. Disability as "exotic or a combination of the exotic and wondrous" (McRuer, 2006 p. 99) is brought into the public consciousness in popular writing and filmmaking. Davis (2006, p. 117) sees these "endless tales" of the media's version of disability as nothing less than a "desperate attempt by people to consolidate their normality." Couser (2006, p. 401) further discusses how the hyper-representation of disability images in popular culture is slowly being

tempered by life writing—both first and third person writing. He states that these accounts can sometimes counter the, too often, “moralizing, objectifying, pathologizing and marginalising representations of disability.”

This review analyzes some of the characteristics of two powerful, popular and widely accessible pieces—Ian Brown’s written series about his son Walker, *The Boy in The Moon*, and Sandrine Bonnaire’s film about her sister, *Her Name is Sabine*, and show how even the seemingly benign work of these two people perpetuates pervasive and negative images and ideas about disabled people, in particular people with cognitive impairments. Over the long term, accounts such as these damage the public imagination as do more overtly discriminatory media coverage, such as the Latimer and Shiavo coverage of the late ‘90s and early twenty-first century.

Appearing publicly in the same year, 2007, the two works in question are a serialized journal and a documentary film. *The Boy in the Moon*, the serialized journal, was first published in a major national newspaper prior to the publication of the book by the same name (to be published August 2009). In this piece, Ian Brown tells the story of his life with his son, Walker, who lives with cardio-facio-cutaneous syndrome (CFC). The written series appeared in *The Globe and Mail* (a major Canadian national newspaper), and appears on its website accompanied by black and white photographs and video clips of Walker at home with his family, as well as pictures of some of the other children with CFC and their families who Brown encounters on his journey to find suitable accommodation for Walker when he can no longer be managed at home.

Her Name is Sabine is an award-winning (six major awards, including Official Selection at the Chicago Film Festival in 2007) and highly acclaimed French documentary film by actress Sandrine Bonnaire about her younger sister, Sabine. Bonnaire uses documentary footage she filmed of Sabine over 25 years, crosscut with present day footage of Sabine and their quest to find suitable living arrangements for Sabine following several years of hospitalization for an undiagnosed/unspecified autism-like impairment. Bonnaire documents the extreme detrimental changes that Sabine has undergone as a result of her hospitalization.

Both pieces are wonderful renderings, beautiful in form and presentation, as reviewers of the documentary and commentators on the series both attest. In the comments on Brown’s piece, posted on The Globe and Mail website, there were more than a few references to the piece being the best thing people had “ever read.” Thus, the content, artistry and form—in Brown, beautiful black and white photographs, moving images and engaging style of writing, and the exquisite images of a young Sabine presented by Bonnaire in *Her Name is Sabine*—contribute to the sense of “acceptability” of the content. Notably, the “choice” placement of Brown’s series in the Saturday edition of the newspaper, when readers typically have more time to spend reading, as well as a stylistically laid out web version complete with video images at the click of a mouse, contribute to the reader’s “pleasurable” experience of reading the series—even though the content may be disturbing or upsetting.

There is, however, more to reading a newspaper and watching a film than simply responding to the pictures and text at face value. Titchkosky (2005) argues that mainstream media sets people up, or organizes consciousness, to perceive disabled people as worthless. At the same time, images of disability are clearly worth something as they help to sell papers and gain an audience as freak shows, disabled characters in comics and images of disabled people in the tabloids attest. Since reading is an embodied act, we “read” with our bodily responses, intuition, emotional triggers, imaginations, etc. In pursuing Titchkosky’s thinking, what is “between the lines” of the text is as much the message as is the text itself. Since none of us are immune to the disability-negative conditioning we receive in the culture, we are ill-equipped, as Titchkosky (2005) describes it, to read the way we read, and are therefore unable to understand just how pervasive and negative the underlying messages from these two pieces are. The viewer/reader is profoundly influenced, not only by the text but also by the meaning in between the lines. Therefore, the overriding theme in both Brown and Bonnaire, of equating difference with defect and tragedy rather than with positive social difference, is subtly shaping and reinforcing our negative perceptions of disability.

Consent, Gatekeeping and Cognitive Ableism

“Who’s voice is heard here is of fundamental concern here.”

—(Moore, Beazley, & Maelzer, 1998, p. 40)

In both pieces the medical/institutional response is at the forefront of the “solution” to the “problems” faced by Sabine and Walker, yet there is no discussion or presentation of the issue of consent—normally such a key factor in all things medical/institutional. There is an underlying presumption that Walker and Sabine would not be competent to consent to being written about or filmed because of their respective impairments. This raises not only the question of consent, but also of how disabled people can be involved in representations of themselves in research, art, and writing (Moore et al., 1998). Brown and Bonnaire must have faced tremendous challenges in these and other works they have produced, in determining who decides what is worth knowing and whose views are worth having? Yet, these questions are not directly addressed in the two works.

There are several reasons why consent and voice are at issue in these two pieces. Both Brown and Bonnaire appear to be acting out a type of *cognitive ableism*, a bias in favour of those who demonstrate cognitive abilities, by *not* privileging the perspectives of Walker and Sabine. As a result of the way the stories are presented, the reader/viewer does not question that it is normal for Walker to be talked about, photographed and filmed, or for Sandrine to be filmed in all kinds of—what could be seen as compromising, and at best, unflattering—positions. We see, for example, Walker smashing his own head violently, and Sabine drooling while the camera does a close-up of her eating a hamburger at McDonald’s.

In both documentary and journalistic practice consent is typically sought from subjects. Yet there is no mention of securing the consent of their subjects by either Bonnaire or Brown, nor do we know if and what consent was sought of Walker and Sabine by the authors. This may be because permission was granted by Brown as Walker’s parent and by Bonnaire as Sabine’s guardian—they might have supposed they did not need to ask for consent. This raises complex issues for disability scholars, professionals and

family members that are beyond the scope of this review, but involve “best interest” determinations. For example, would Walker and Sabine’s right *not* to be exposed in all their vulnerability supersede Brown and Bonnaire’s right to tell their story? Or are there ways that the stories could have been told without exposing/emphasizing those vulnerabilities?

Ervelles (2002) describes people with cognitive impairments as an underclass within an underclass, and addresses the continued exclusion of people with cognitive and severe impairments in our culture. She suggests there is little interest in the citizenship rights of people with cognitive/severe disabilities except in discussions/determinations of how severely disabled a fetus might be. Ervelles contends that the issue of consent may not even come into play, as it does not with Bonnaire and Brown, because people assume it is not attainable. It is this writer’s contention that, were it not for the cognitive impairments of both Walker and Sabine, the public would not so willingly accept exposing them in the ways Brown and Bonnaire do, without their *explicit* informed consent.

Did Brown try to get Walker’s consent, as he might have from his non-disabled daughter, Hayley, if he had wanted to tell her story in the newspaper, the story of having a sibling like Walker? Did Bonnaire show footage to Sabine of her tearful reaction to seeing herself as a young woman on a plane and get her consent to include it in the documentary? Was there a discussion with Sabine or Walker about confidentiality? Was either given the opportunity to give or refuse consent? Do these questions even come to mind when the average viewer/reader approaches these pieces? None of the 172 written comments to the Globe article, posted on The Globe and Mail website from the time it was originally published in December 2007 through March 2008, addressed or asked questions about Walker’s consenting to be written about, filmed and photographed for *The Boy in the Moon*. As well, none of the seven reviews or descriptions I read of *Her Name is Sabine* raised consent issues—in fact, a review in *Variety Magazine* (Nesselson, 2007) described the film as “intimate, but never transgressive,” fully not appreciating just how violating of Sabine’s personal boundaries (transgressive) and intrusive the film may be other from other than an ableist perspective.

Whose Story is it to Tell? Who has Access to the Media?

Walker and Sabine should be allowed to have their stories told from their own perspective, but they do not have access to the means to tell them or to have them told. Both Brown, as a major Canadian journalist—he not only writes, but hosts a documentary series on public television—and Bonnaire, as an award winning French actress, however, have extraordinary access to the media. With their elevated status they are able to present the “stories” of Sabine and Walker as they wish. It is not so much what they say in these pieces, but *how* it is said, *how much* it is said, and *how much space* it takes up in the world compared to real stories with disabled people at the centre, that has the most significant consequences.

It is not that we never “see” the real Walker and Sabine in these stories. At one point, when returning to his group home, Walker takes his parents hands to firmly escort them out—it is obvious he wants them to leave and is communicating that loud and clear. In another example, we see Sabine as she keeps lying down to “rest” in the garden and asking for a break when she is supposed to be working and then is coaxed out of her reverie by her attendants. These are two of the few times we see that Walker and Sabine have agency. However, it is difficult to imagine other possibilities for Sabine and Walker’s lives when presented with the narrow focus on what is *wrong* (Titchkosky, 2005) with Sabine and Walker in both works.

What would Sabine’s story have looked like if she were able to tell it herself? What if she or her advocates had had access to the media during her institutionalization, where she sustained long-lasting effects from the over-medication that Bonnaire decries in the film? Imagine if Bonnaire were to give her filmmaking money to a disabled filmmaker or an advocate for Sabine—would the film have been any different?

With that option being unlikely, the messages that underpin these stories are caught up with Brown’s and Bonnaire’s attitudes about the lives of Walker and Sabine. These are not innocuous messages, on the contrary, they serve to reinforce our sense of fear, disgust,

pity, and make it possible for us to further entrench attitudes which inadvertently reinforce dominant notions of disability and how it should be dealt with (Hershey, 1993).

One might suppose that any representation of disability, other than overtly discriminatory ones, might be a positive movement forward in today’s culture. Brown and Bonnaire are bringing a different, sympathetic, gentle, understanding view of their subjects, which could be seen as liberatory, but at the same time the overall impact is oppressive, leaving the reader with the overriding impression—a dangerous one for disabled people—that institutionalization is a justifiable alternative to community living.

Voyeurism and the Enfreakment of Sabine and Walker

Both the Brown and Bonnaire pieces are voyeuristic and portray Walker and Sabine as objects of curiosity. One might say that any biopic or story depicts people as objects of curiosity, but with disabled people the general public has little insight into the environmental and social barriers that prevent them from living full and active lives (Barnes, 1992). Without this context there can be no comparison and the subject becomes one-dimensional without the viewer/reader having access to the range of emotions and complexity of the subject’s lives—for example, the multiple roles they may play as sibling, mother, friend, playmate, gardener, cook, reader, comedian, etc. Although both Bonnaire and Brown attempt, in their pieces, to provide the context, it is accidental instead of purposeful background, one might say, to the “real” story which is the one-dimensional presentation of the disabled subject as “burden” or “curiosity.”

These portrayals of a disabled person do what Garland-Thomson (1997:12) describes as “cancel[ling] out other qualities, reducing the complex person to a single attribute” and contribute to the “enfreakment” of Sabine and Walker. In presenting Sabine and Walker from, what Garland-Thomson (1997) calls the normate position, both Brown and Bonnaire do nothing in their portrayals to disrupt this enfreakment or the normal/abnormal binary of their subjects who are in the disabled position. Rather, they

“buttress our embodied version of a normative identity” (Garland-Thomson, 1997, p. 7). Brown does so with his use of negative and enfreaking descriptors of Walker—compromised child, burden, handicapped, sickness, new human strain, physically impossible, deleterious effect (describing the “faulty” gene responsible for Walker’s impairment), truly unfixable, nightmare—and in describing another child as “a less afflicted version of Walker” (Brown, 2007: Pt. 2, Ch. 4), and Bonnaire, through the unflattering close-up images of Sabine drooling or eating, staring vacantly, asking her the same question over and over again, etc.

Normalcy is etched into our collective cultural unconscious. Brown and Bonnaire are what might be called the mediating narrative voices that present us with the freakish spectacle of Walker and Sabine. We are seduced, in the reading and viewing of the pieces, into thinking that we are seeing Sabine and Walker’s lives when we are viewing only a fraction—the images the author wants us to see and which function as a lightning rod for pity, fear, discomfort, guilt or sense of normalcy for the reader. This suggests that these portrayals are a postmodern “grotesque”—appearing under the guise of enlightened, analytical, and neutral (though personal) journalistic presentation.

Neither Bonnaire nor Brown would appreciate the fact that they are being described as “enfreaking” their own sister and son, but in light of the current Western cultural emphasis on beauty and our horror of aging and the accompanying disablement, pieces like these play a role in reducing our collective anxiety about difference by helping us to distance ourselves from the “other.” As viewers, or voyeurs, we are tricked into believing that the images in these stories are progressive and disability-positive. There is beauty in what Brown writes and in the magnificent moving and static images of Walker on the website. The glorious images presented of Sabine of her ‘normal’ childhood are seductive and keep us transfixed, waiting with baited breath to find the “cause” for the way she is today. The images of the disabled Walker and Sabine make us feel more ‘normal’ in contrast (Garland-Thomson 1997).

The Impact on the Reader/Viewer

It is difficult to determine the impact these two pieces have on the reader/viewer but there are some indications—particularly in the case of the Brown series. While both pieces are able to elicit strong emotional responses in the reader/viewer, one suspects the primary response is one of overwhelming sympathy for the documentarians and their challenges and dilemmas—rather than one of empathy with the subject. Practically all 172 comments in response to the Globe series suggest this to be true. One can only speculate on the response of readers/viewers to the notion of rights to full citizenship for both Sabine and Walker—which would include rights and entitlements not to be exploited in the media without recourse. Very few commentators on the Brown piece on the Globe website explicitly addressed the need to take action for systemic change, or expressed concern that this might be an issue—barely a handful even mentioned the social issues and barriers facing Walker and his family. The overwhelming tone and content of the responses had to do with expressing sympathy for Brown for his “dilemma”; congratulating him for his familial “devotion: for being such a wonderful, caring, sacrificing, loving parent”¹; and thanking him for reminding people to “hug our own [presumably non-disabled] children” (Leslies, 2007) a little harder after reading the series. To an audience who understands the context of the lives of disabled people and the function of normalcy in keeping disabled people, particularly those with cognitive impairments, marginalized in our society, these pieces illustrate that when disabled people are not at the centre the results can be devastating (Moore et al., 1998).

Conclusion

We need to look beyond what Brown and Bonnaire say in these pieces to discuss how their social power and their privileged access to mainstream media perpetuate images and notions of disabled persons as “other” and deviant. We need to challenge writers and filmmakers who, like Brown and Bonnaire,

1 Editor’s note: Words, like “devotion,” “sacrifice,” “dilemma” and others were used repeatedly in the letters to *The Globe and Mail* editors.

present disabled lives as truth in ways that evoke notions of the spectacle and sentimental fiction, appealing to a wide audience and further entrenching assumptions of difference and otherness of disabled people.

These stories fix in our minds these stigmatized versions of Sabine and Walker, where both are denied opportunities for subjectivity or agency (because, otherwise, there may not be a story). Under the guise of being progressive enlightened pieces, the journalistic series *The Boy in the Moon* and the documentary film *Her Name is Sabine*, contribute significantly to maintaining disablist attitudes and notions of the superiority of the normate for the reader/viewer. Though this may not be the intention of the authors, it nevertheless may be the result. Both pieces are epic responses to questions that could and should be answered in a more disability-positive, subject-centred way. If Walker and Sabine are truly citizens of the world, then they should be allowed to be seen in all their complexity—with their consent. With no evidence of explicit consent or perspective from the subjects, alongside the positioning of the reader/viewer as voyeur, these two powerful, accessible, popular pieces are working to the detriment of disabled persons. Disability scholars and advocates need to sharpen our “reading” tools and not take these pieces lightly, but rather challenge the disablist and disability-phobic notions that they put forward. We also need to continue to push for those changes and resources which will enable disabled people to gain equal access—including access to mainstream media which is so instrumental in shaping perceptions and attitudes about disability in our culture.

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