

Affective (Dis)Ability:

Ian Brown's Search for "Inner Life" in *The Boy in the Moon*

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The author would like to acknowledge Professor T. Kenny Fountain for his insight and feedback on early drafts of this essay.

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Citation

Orlando, M. Affective (dis)ability: Ian Brown's search for "inner life" in *The boy in the moon*.

Critical Disability Discourse/Discours Critiques dans le Champ du Handicap 5, 94–119.

Abstract

This essay examines a father's quest to find proof of the "inner life" of his physically and cognitively disabled son in Ian Brown's memoir *The Boy in the Moon: A Father's Journey to Understand His Extraordinary Son*. Through literary analysis and close attention to relevant theories of affect and disability, this paper explores the influence of dominant social and cultural narratives about normalcy and emotion on understandings of disabled lives as well as the limitations of current theories when it comes to recognizing the affective potential of those who fall outside what is considered the zone of normal physical, mental, and emotional experience and expression. I argue here that Brown's quest to understand his son's affectivity leads him toward a greater recognition of possibilities for human relationship beyond the intellectual or verbal. I find that the trajectory of Brown's personal quest has important repercussions for the ways that theories of affect and disability studies can be productively brought together to formulate understandings of intersubjective and interdependent affective relationships for people with cognitive disabilities.

Keywords: disability, affect, emotion, memoir, Canada

L' (in)capacité affective:

La quête de Ian Brown pour la « vie intérieure » dans *The Boy in the Moon*
Cet article examine la quête d'un père pour comprendre la « vie intérieure » de son fils physiquement et cognitivement handicapé, dans les mémoires de Ian Brown, *The Boy in the Moon: A Father's Journey to Understand His Extraordinary Son*. Grâce à l'analyse littéraire et à une attention particulière portée aux théories pertinentes de l'affect et de l'invalidité, cet article explore l'influence des récits sociaux et culturels dominants sur la normalité et l'émotion pour

comprendre les vies des personnes handicapées , ainsi que les limites des théories actuelles quand il s'agit de reconnaître le potentiel affectif de ceux qui n'entrent pas dans ce qui est considéré la zone d'expérience et de d' expression physique, mentale et émotionnelle, normale. Je soutiens ici que la quête de Brown pour comprendre l'affectivité de son fils l'amène vers une plus grande connaissance des possibilités de relation humaine au-delà de l'intellectuel ou du verbal. Je propose que la trajectoire de la quête personnelle de Brown a des répercussions importantes sur les façons dont les théories de l'affect et les études d'invalidité peuvent être productivement réunies, afin de r formuler des interprétations de relations affectives intersubjectives et interdépendantes pour les personnes ayant une déficience cognitive.

Mots-clés: handicap, affect, émotion, mémoire, Canada

Affective (Dis)Ability:

Ian Brown's Search for "Inner Life" in *The Boy in the Moon*

Much of the theory surrounding affect and emotion assumes a certain level of "normalcy" in terms of cognitive and physical ability, emotional experience, and the use of language to communicate thoughts and feelings to others. However, many of these theories are challenged or complicated when one seeks to apply them to people with disabilities—particularly intellectual and severe physical disabilities—who may not function at normative levels of cognitive, social, or linguistic engagement. The emerging field of disability studies might seem a natural place to look for ways to talk about emotion and difference; however, attention to emotion is often minimal in scholarly conversations in disability studies, which tend to focus more prominently on visible, physical aspects of disability and on the social constructions of these types of disability. Therefore, it can be difficult to know where to place physical and cognitive difference in broader conversations about affect and emotion. This essay will investigate one author's attempt to understand the emotional life of his physically and cognitively disabled son, and use this exploration to forge some connections between affect theory, disability studies, and parent memoir about children with disabilities.

How can we best understand the affective, emotional, or otherwise "inner" lives of people with cognitive disabilities, particularly those who cannot speak? This is the main question that Canadian journalist Ian Brown seeks to answer in his memoir *The Boy in the Moon: A Father's Journey to Understand His Extraordinary Son*, which chronicles his experience as the father of Walker, a child with significant physical and cognitive disabilities as a result of

cardiofaciocutaneous syndrome (CFC).¹ Throughout the book, Brown both shares the difficulties and joys of life with Walker and describes his own journey to comprehend the value of a life like Walker's. Brown is concerned with finding proof of Walker's "inner life," of internal awareness and emotion, in spite of the cognitive disability and lack of speech which make it impossible for Walker to communicate anything about that inner life in any explicit way to other people. In this essay I will demonstrate that in his search for Walker's inner, affective life, Ian Brown contends with influential cultural narratives about mental and physical normalcy as well as with dominant theories about human emotion and the ability to affect and be affected by others. I argue that, by the end of his text, Brown finds these standard narratives and theories to be largely insufficient and realizes that to some extent, his connection with Walker and Walker's affective life lie outside the limits of such theories. Though Brown's book only chronicles his own attempts to understand the emotions of his disabled son, I contend that in beginning to recognize the value of intersubjective affective experience, rather than only the standard conceptions of intellect and individual emotion, Brown's quest points toward promising possibilities for the theorizing of affect and humanity beyond the boundaries of "normal" human experience. This shift expands not only the preconceptions of ability and disability in society at large, but also pushes disability studies beyond its tendency to theorize primarily about physical disability to a greater consideration of both intellectual difference and the power of emotion in understanding disabled lives.

¹ CFC, a genetic disorder, is believed to affect at most a few hundred people in the world. The symptoms differ somewhat from person to person, but always include some variation on the areas referenced in the syndrome's name: "*cardio*, for ever-present murmurs and malformations and enlargements of the heart; *facio*, for the facial dysmorphia that was its signal characteristic, a prominent brow and down-sloping eyes; *cutaneous*, for its many skin irregularities" (Brown, 2009, p. 8). In addition, nearly all people with CFC have some level of cognitive impairment, and many, including Walker, cannot speak.

Considering Affect and Disability

Early on in *The Boy in the Moon*, Brown spells out the broad strokes of his search regarding his “extraordinary son,” Walker: “What is the value of a life like his—a life lived in twilight, and often in pain? What is the cost of his life to those around him?” (p. 3). This general objective shapes Brown’s journey in the text as he investigates the meaning of Walker’s anomalous life. In addition, Brown’s more specific interest soon comes into view: “What I cared about was whether he had a sense of himself, an inner life. Sometimes it seemed like the most urgent question of all” (p. 48). This question drives Brown as he seeks to interpret Walker’s emotions, examines his own affective responses to his son, and pursues alternatives to the standard and often limiting narratives about what it means to be human, which hold out little hope for someone as different from the “norm” as Walker.

The issue of whether or not Walker has an “inner life” is a complicated one, both from a general and from a disability studies standpoint, as it raises questions about how we understand and recognize the humanity of those who are different from us, especially those with whom we cannot communicate in direct or traditional ways. Brown’s questions, above, indicate the difficulty of comprehending how a severely disabled person can have a worthwhile life, and not be a burden to others, in a culture that prefers and prioritizes the able-bodied and able-minded. Disability theory regarding ableist assumptions about embodiment and normalcy is helpful in recognizing some of the damaging effects of these assumptions, and highlights the sorts of conventional narratives that Brown must resist in order to recognize the worth of his son’s life. Perhaps the most dominant of these narratives is what Tobin Siebers (2008) refers to as the “ideology of ability,” defining it as “at its simplest the preference for able-bodiedness. At its most radical, it defines the baseline by which humanness is determined, setting the measure of

body and mind that gives or denies human status to individual persons” (p. 8). Brown’s project in *The Boy in the Moon* provides a site for figuring out how to define human status or worth as well as for grappling with the ideology of ability’s eagerness “to attack any desire to know and to accept the disabled body in its current state” and “to insist that the body has no value as human variation if it is not flawless” (Siebers, 2008, p. 26).

Though Siebers mentions measures of both “body and mind,” his primary focus is on the treatment of those with physical disabilities. This concentration on physical difference is common in disability scholarship, in large part because of disability studies’ growth out of the disability rights movement, which began with the immediate concerns of rights and access for those with physical impairments. While the disability rights movement naturally had to have a starting point, ableist treatment is comparable, if not intensified, for those with mental disabilities, whether intellectual, neurological, or psychiatric, and this area of disability deserves greater attention than it has typically received. Michael Bérubé (2004), whose son has Down syndrome, comments, “Since [my son’s] birth, I’d been struck by the relative invisibility of people with developmental disabilities in the general culture, an invisibility that is being remedied only slowly and fitfully” (p. 496). More bluntly, Mark Osteen (2008) accuses disability studies of a form of “cognitive ableism—a prejudice against those who cannot compose articles and books, compete for advocacy space, and contribute to disability scholarship” (p. 5). I agree with Osteen’s point; many of those with mental disabilities are unable to advocate for themselves and therefore have less of a chance of representation in disability studies or disability rights efforts. As a result, the possibilities for individuals with intellectual disabilities, both real and perceived, are even further limited than for those with physical disabilities, a fact which requires individuals and those close to them to deal with the improbability of living up to cultural and

social expectations about what comprises a fulfilling and worthwhile life. Though there has been a movement toward greater inclusion of mental disabilities in disability studies in recent years, including Margaret Price's (2011) seminal work on mental disability in the academy and Cynthia Lewiecki-Wilson's (2003) discussion of rhetoric and mental disability, there is still a great deal of room for the development of disability studies scholarship regarding the rights and representation of people with mental disabilities.

In addition to the frequent exclusion of cognitive and intellectual disabilities, there has been little exploration of affectivity and emotion in disability studies scholarship. As internal, largely invisible aspects of experience, affect and emotion are aligned with the often invisible presence of mental disabilities. Elizabeth Donaldson and Catherine Prendergast (2011) complain: “[I]ronically, Disability Studies, forged as it has been with physical impairment as its primary terrain, has inherited damaging ableist assumptions of ‘mind’ that discourage a more robust consideration of emotion” (p. 130). These silences leave a space that needs to be filled in discussions of the affective lives of people with intellectual disabilities and the possible contribution of affectivity to a view of the disabled as valuable members of human society. Recognizing the role of affect and emotion in human relationships can be productive in our understanding of disability in general, but particularly in understanding and recognizing the humanity of people with mental disabilities who may be overlooked even by disability studies due to the sort of cognitive ableism noted by Osteen and others. Academia must stretch beyond normative conceptions of intelligence and intellectualism and recognize the value of those who may not write, publish, or even speak, but who are equally human and have “inner lives” and affective capabilities, whether or not those are recognized by the able-minded.

Some recent work in disability studies has made use of affect in studying attitudes toward people with disabilities, both physical and mental. However, these studies often call attention to the presence or influence of negative affect, a trend which I see as reversed in Brown's book. Dilia Narduzzi (2013), for instance, in her analysis of Alice Munro's short story "Child's Play," discusses the way negative affect toward a child with physical and possibly mental disabilities leads two other children to commit violence against the disabled girl. Narduzzi discusses the role of affect in the creation and perpetuation of ableist norms, arguing that in the story, "[C]ultural norms are replicated *through and by* the normalization of particular affects and affective responses to disability" (p. 72). This attention to how affect influences attitudes toward those with disabilities makes a significant contribution to disability studies scholarship in that it enables a deeper understanding of the role of emotion in human relationships involving disability, but its focus is limited to negative affective responses. John Duffy and Rebecca Dorner's (2011) thoughtful discussion of the ableism inherent in the Theory of Mind explanation of autism popularized by Simon Baron-Cohen demonstrates the prioritizing of a certain kind of affect in efforts to define what it means to be human. Similarly to Brown's quest, Duffy and Dorner note that narratives of autism often ask, "What forms of thinking, living, speaking, and relating to other human beings are possible for [autistic people], and which forms are not?" (p. 205). Through the development of the concept of "mindblindness," the Theory of Mind narrative separates the autistic mind from the neurotypical one by emphasizing autistic people's affective difference or inability and posing it as a reason for pity. Duffy and Dorner argue that "[w]hat Baron-Cohen and other ToM [Theory of Mind] advocates create... is a rhetoric not of identification with autistic people, but rather a language of differentiation and division that

speaks to the strangeness, terrors, and desolating sadness of autism” (p. 211). Affect here, as in Munro’s story, is used a tool for othering those with disabilities.

While both Narduzzi’s and Duffy and Dorner’s arguments focus on the use of affect to confirm difference and maintain distance between able and disabled, between normative and other, in my analysis of *The Boy in the Moon* I would like to demonstrate how attention to affect can reveal new ways of recognizing the severely disabled “other” as fully human and capable of human relationships. As Brown searches for a way to understand his son whose disabilities defy narratives of normalcy, affective experience provides a way for him to connect with Walker and come to recognize his son’s humanity in his ability to enter into intersubjective relationships through affectivity, and his account in his memoir helps demonstrate this possibility to readers as well. In order to reach that point, however, Brown must work through cultural narratives about normalcy and emotion that make such a recognition challenging.

Narratives of Normalcy and Happiness

Like many parents of disabled children, Brown and his wife, Johanna Schneller, struggle with the disappointment of knowing that Walker will never be able to do some of the things that parents generally dream of for their children. As Alison Piepmeier (2012) observes, “Many of the [parent] memoirs voice the grief over the loss of the idealized perfect child who wasn’t born.” Though I argue that Brown’s grief is less significant in his work as a whole than in some parent memoirs about disability, it does underlie his effort to understand his son who doesn’t fit the model of the “perfect child.” At one point Brown reflects on never being able to hear Walker speak: “[T]o hear him speak his own name?...To hear him say, *Ma, I love you?* My heart is banging at the thought. *Fuck you, Dada!* would be the Gettysburg Address” (p. 124). Lack of speech, just one feature of Walker’s disability, precludes the kind of “normal” interaction

expected between a child and his family, expressions of love as well as of anger. Walker's other cognitive and physical disabilities prevent him from many other milestones of life that parents look forward to for their children: Johanna asks a developmental pediatrician, "Will he ever be able to read? Or...drive a car?" (p. 67). (The answer given is "no" to both.) It becomes clear to Brown and his wife that such expectations of normalcy are not realistic for Walker, and giving up on these expectations is painful. The cultural ideals of independence, productivity, and a particular narrative of success are difficult to relinquish.

Sara Ahmed's examination of cultural expectations in her book *The Promise of Happiness* (2010) touches on these same normative conceptions of how one can and should be "happy." Though she does not directly address disability, her attention to female, black, and queer experience represents the same sorts of marginalization of non-normative identities as those displayed toward people with physical and intellectual disabilities. Ahmed sets up her discussion to interrogate, in part, "how happiness is imagined as being what follows being a certain kind of being" (p. 2). A disabled person like Walker is often not seen as the "kind of being" who is capable of achieving happiness in a normative sense. Ahmed states that her goal in the book is in some sense to "kill joy," or at least conventional ideas of what joy is: "To kill joy, as many of the texts I cite in the following pages teach us, is to open a life, to make room for life, to make room for possibility, for chance. My aim in this book is to make room" (p. 20). The kind of "making room" that Ahmed is doing allows for the possibility of happiness, of valuable life, that is associated with identities that do not fit into normative notions of "happy" identity, in terms of race, gender, sexuality, or ability.

Ahmed also addresses the issue of parents' expectations for their children, particularly children who differ in some way from the norm. Expanding on her idea that happiness is seen as

following certain ways of being, she discusses socially-constructed ideas of “a certain kind of life, one that reaches certain points, and which, in reaching these points, creates happiness for others. The family is after all ‘where’ the child is cultivated, where the child learns the right habits, which, in turn, render some objects as happy for the child” (p. 48). The family, then, is held to have some sense of involvement, both responsibility and reciprocity, in the child’s happiness, and passes on ideas about the objects that should create happiness, such as independence, marriage, and children of one’s own. Disabled children’s perceived (or actual) inability to achieve the objects traditionally associated with happiness may lead to parents’ unhappiness, or fear of unhappiness, for their children. Brown’s wife Johanna, who seems to struggle more with acceptance of Walker’s disability than does Brown, makes a confession to her husband that is representative of such fears:

“I hear parents of other handicapped kids saying all the time, ‘I wouldn’t change my child,’” Johanna said one night as we were lying in bed, talking as we fell asleep. “They say, ‘I wouldn’t trade him for anything.’ But I would. I would trade Walker, if I could push a button, for the most ordinary kid who got Cs in school. I would trade him in an instant. I wouldn’t trade him for my sake, for our sake. But I would trade for his sake. I think Walker has a very, very hard life.” (p. 80)

Johanna justifies her willingness to trade her “extraordinary” son for an “ordinary” one by her sentiment that Walker’s life is “hard,” which may be understood as code for “unhappy.” Yet Johanna bases her evaluation of the difficulty of Walker’s life on conventional notions of a “good life,” of what it means to be happy— notions derived from an able-bodied and able-minded perspective. It is undoubtedly difficult to separate oneself from one’s own point of view, or from the influence of the cultural and social narratives and ideologies that are unconsciously

inscribed in one's value system. However, it is possible to become aware of the presence of these ideologies and to begin to recognize the possibilities for other ways of living and of being happy.

De-Normalizing Affect

For Brown, recognition of the possibility of other kinds of happiness begins with awareness of different kinds of emotional experience on the part of his disabled son. Throughout the book, Brown is determined to find "proof of an inner life, evidence that [people with CFC] can sense context, that they have desires" (p. 124). Brown's conviction that his preconceived idea of inner life is required in order for his son's existence to be worthwhile is an extension of the narratives of normalcy discussed above. Although he may not explicitly recognize it, Brown's quest is the product of social narratives about what comprises a worthwhile human life and what objects of happiness, or value, are attached to it.

Walker's compound physical and intellectual disabilities, along with his inability to speak, make his emotional experiences particularly difficult for Brown to determine, and it is of course always difficult to conceptualize the emotions of anyone outside of oneself, particularly those who are so different from oneself as to seem almost inscrutable. The seventeenth-century Dutch philosopher Benedict de Spinoza's *Ethics* (1677; trans. 1996) outlines a theory of affect that is relevant to both an understanding of our own affective experiences and our interaction with or insight into those of other people. Spinoza's theory, in direct contrast to the influential concept of mind-body dualism established by René Descartes, emphasizes the interconnectedness of the body and mind and the involvement of both of these elements in the experience of affect. Spinoza defines affect itself as an influence on the body's capacities, "affections of the body by which the body's power of acting is increased or diminished, aided or restrained, and at the same time, the ideas of these affections" (p. 70). Affect, then, is

simultaneously an experience of the body and of the mind. Additionally, Spinoza asserts that one's own experience is central to any attempts at awareness of individuals outside of oneself: "*The human mind does not perceive any external body as actually existing, except through the ideas of the affections of its own body*" (p. 50, italics original). Spinoza's view of affect as monistic, experienced in the unified substance of body and mind, but also particular, unique to the experience of each individual, is pertinent to Brown's vexed attempt to understand his son's affective life, since he himself is inevitably limited by his own mental and bodily affective experiences.

Brown makes many attempts to interpret Walker's behavior, based on his knowledge of his own feelings and emotions, but he must adjust his evaluations according to his observations of Walker. Such attempts at interpretation are critical to efforts to care for Walker in the best way possible, but this uncertain territory must be navigated without the benefit of linguistic communication. Trying to prevent Walker from engaging in his frequent self-injurious behavior is the most direct of these efforts. Because of the frequency and severity of his self-injury, Walker's parents, doctors, and other professionals make countless attempts to interpret the reasons behind the behavior in order to develop a way to prevent it. Most theories revolve around the idea of Walker's frustration about his difference or his inability to express himself verbally: "*He needs stimulation, ' the psychologist says, by way of explaining why he hits himself. How she knows this I have no idea. 'We want his hitting to be more of a choice*" (Brown, 2009, p. 85, italics original). A teacher says, "*He is intrinsically motivated. He's obviously getting something out of it*" (p. 94, italics original). Brown himself submits a few hypotheses: "Because he wants to talk, but can't? Because—this is my latest theory—he can't do what he can see other people doing?" (p. 5). All of these explanations are based on the conjecturer's own experiences—what

each one might be feeling were he or she in Walker's position—with the likely addition, in the case of the professionals, of knowledge of other individuals similar to Walker. Even this sort of “professional” evidence, however, would seem limited in its usefulness; there are few known individuals with CFC, and even among that population there is much variation in physical and intellectual ability, not to mention differences in personality. Brown speaks directly to this need to interpret Walker's behavior, and the difficulty of doing so:

Sometimes Walker was in agony as he smacked himself and screamed with pain. At other times he seemed to do it more expressively, as a way to clear his head, or to let us know he would be saying something if he could talk. Sometimes—and this was unbearably sad—he laughed immediately afterwards. He couldn't tell us anything, and we had to imagine everything. (p. 77)

Their “imagining” is clearly shaped by standard narratives of emotion, particularly the assessment that Walker's laughing after injuring himself is “unbearably sad.” However, in the absence of any other verifiable discourses about emotion, Brown and others can only use the tools at their disposal to respond to and attempt to interpret what they see in Walker. Walker is unable to describe either his motivation or his sensations, and this complicates both the efforts of others to interpret his actions and their more general endeavor to discern the kind of affective life of which Walker may be capable.

Eric Shouse's (2005) theory of affect, emotion, and feeling offers one technique for reading the emotion of others, including those at different developmental levels. Shouse sets up a sort of hierarchy of affectivity, with affect, the most abstract, as the foundation. He adopts Brian Massumi's definition of affect as a “nonconscious experience of intensity,” something unable to be “fully realised in language” because it is always “prior to and/or outside of consciousness”

(Shouse, 2005, para. 5). According to this notion, all people experience the intensities of affect, and no one is fully conscious of or able to represent that basic affective experience in language. Shouse goes on to make distinctions between affect and the related concepts of feeling and emotion, based on level of development. While the abstract and nonconscious intensities of affect are experienced by everyone regardless of age or ability, Shouse limits the pool of people capable of experiencing feeling and the more conscious form of emotion. As Shouse defines it, feeling is personal, “a sensation that has been checked against previous experiences and labeled”; in his estimation, “An infant does not experience feeling because she/he lacks both language and biography” (para. 3). Instead, Shouse claims, infants can only experience the prepersonal intensity of affect, and their social expression of emotion, the “projection/display of a feeling” to others (para. 4) can only be an unmediated, direct expression of that affect. Adults, on the other hand, in Shouse’s view, have developed the ability to control their emotional displays and choose which of their inner feelings to convey to others.

Shouse’s categorizing system raises significant questions about whether someone like Walker is capable of moving beyond affect to feeling, and whether, or how much, this matters. Shouse requires “language and biography” in order for a person to be able to compare a sensation to past experience and label it as a particular feeling; Walker does not have a command of language, at least as far as others can tell, and it is also unclear whether he is cognitively able to recall and make use of his past experiences. Shouse’s formulation of affect, feeling, and emotion suggests that Walker’s capabilities may be extremely limited, perhaps at the same level as an infant, which again poses questions about what level of affectivity may be required for classification as “fully human.” Antonio Damasio (1994) also sets up a developmental division in his study of affect and emotion: what he refers to as primary (early) emotions, and secondary

(adult) ones. Primary emotions are those one is typically capable of experiencing early in life, including “Happiness, Sadness, Anger, Fear, and Disgust,” while the secondary emotions are more sophisticated or nuanced versions of the primary emotions: for instance, “euphoria and ecstasy are variations of happiness; melancholy and wistfulness are variations of sadness” (Damasio, 1994, p. 149). Damasio does not specifically mention cognitive disability, but he does note that “emotional processing impaired with prefrontal [brain] damage is of the secondary type” (p. 149), meaning that those with certain brain injuries are thereafter only able to experience the primary emotions.

Based on this model, and the fact that Walker’s brain is identified in medical terms as abnormal², one might surmise that Walker is capable only of primary emotions in Damasio’s sense, although there is no way, and ultimately no necessity, of definitively determining this. However, whether or not he is capable of complex adult emotions, Walker’s emotional displays are observable (though subject to interpretation) and clearly representative of inner affective realities. And according to both Spinoza’s and Shouse’s conceptions of affect, transmission of affect between individuals can take place without either emotional sophistication or language. Shouse grants that “[e]very form of communication where facial expressions, respiration, tone of voice, and posture are perceptible can transmit affect...” (para. 13). Despite Walker’s inability to communicate his feelings verbally, the transmission of affect between him and others can clearly still occur. It is important to recognize the potential ableism inherent in categorizing emotional levels as “primary vs. secondary” or “infant vs. adult,” as such labels indicate that one must meet certain normative requirements in order to be considered at the proper level of development.

² An MRI reveals that Walker’s brain has an underdeveloped corpus callosum, signifying a lack of connectivity between the left and right brain; insufficient furrows in the hippocampus; and smaller-than-normal amounts of both white matter and grey matter. Brown, however, takes little from this information: “[H]is brain had even less to tell me about who Walker was and how the world appeared to him than I knew myself” (p. 279). Scientific evidence becomes gradually less important to Brown than his observations and lived experience with Walker.

Walker's development and abilities may be different from those of other children his age, and may continue to be different throughout his life, but his disabilities do not preclude his humanness or his ability to engage in affective transmission with others.

One way that this affective transmission appears to occur between Brown and Walker is through nontraditional (and necessarily nonspecific) means of communication. Brown writes of his "click language" with Walker, a language that only he and his son use, in which they make clicking sounds at one another to indicate a kind of kinship between the two of them, a basic level of awareness of one another's emotional state. Through this "language," Brown is able to decipher some of Walker's emotional reactions, and guess at others, and the abstract intensity of affect seems to be able to fill in the gaps where specific communication is not able to take place:

As he grew older, we developed a private language of tongue clicks that only he and I speak. All we ever seem to say is, "Hello, it's me, I'm clicking to you, and only to you, because only you and I speak Click"; to which he (or I) reply, I think, "Yes, hi, see you there, and I am clicking back, I like it that we speak our private language, in fact I find it hilarious." This is very enjoyable for both of us. (p. 34)

Brown has developed an interpretation of what the click language is saying, and likely Walker has his own understanding of what it means or what it does. However, the evaluation, "This is very enjoyable for both of us," is revealing. Even if there are no specific pieces of information passed through this basic form of communication between Walker and Brown, there is positive affect being transmitted. The recognition of this sort of affective relationship between disabled and able bodies and minds is a starting point for a positive alternative view of the power of affectivity for people with intellectual disabilities.

Alternative Narratives of Ability, Affectivity, and Value

Brown devotes a large section toward the end of his memoir to his interaction with the L'Arche community and its founder, Jean Vanier, an experience which leads him toward a new impression of the possibilities for relationship and affectivity between people with and without disabilities. L'Arche is an international network of communities for people with disabilities and able-bodied assistants, founded by Vanier in France in 1964. Vanier's philosophies about the value of intellectually disabled people and the affective relationships they are capable of having with others, including able-bodied and -minded people, provides an alternative to the problematic discourses with which Brown contends in the search for his son's worth recorded in his book. While theorists like Spinoza provide a means of recognizing the possibility of affective transmission between bodies and minds regardless of physical or mental ability, none of the affect theorists I have encountered speak directly to the specific nature and intricacies of disabled affectivity, and as I have noted above, disability theory has also largely failed to examine intersections between emotion and disability. An outlier from the fields of either affect theory or disability studies, probably in part because of his foundation in Catholic theological principles, Vanier provides a glimpse into a promising alternative view of people with intellectual disabilities and the potential for their positive affective relationships with nondisabled people. Brown, an atheist, expresses some reservations about Vanier and L'Arche because of their religious underpinnings, but both the ideology and practice of L'Arche seem to stand on their own, and the potential benefits of Vanier's view of the disabled may offset for Brown the drawback of its identification with religion. Brown comes to see L'Arche as a kind of ideal both for communities for people with disabilities and for the trajectory of society in general in its treatment of disability—in both senses, a “possible future for Walker” (Brown, p. 194).

Upon entering the meeting place of the Montreal branch of L'Arche, Brown immediately recognizes the uniqueness of this space: "I saw for the first time the outline of the unthinkable community I was looking for. In that community, *I* was the stranger" (p. 187). In this "unthinkable community," the disabled outnumber the able and are considered integral members of the community in a way that is inconceivable to most of conventional society. Many times throughout the book, Brown laments the lack of social interest in or care for the intellectually disabled; for instance, when Walker's school for the disabled is about to be shut down, Brown complains, "[T]he government's priorities are clear: the disabled don't vote, and so don't deserve much individual attention. They don't fit the formula—any formula" (p. 88). However, at L'Arche the disabled seem to fit an alternative formula. Vanier's philosophy is based on the principle that all human beings are weak and vulnerable, and they must accept their own weakness by accepting it in others. The recognition of common weakness in the L'Arche model allows for the possibility of full and satisfying relationships between disabled and nondisabled people. After meeting with Vanier personally, Brown characterizes Vanier's view in the following way:

Every time we meet someone who is severely handicapped, Jean Vanier believes, they ask two questions: Do you consider me human? Do you love me? The more we meet the handicapped on their own ground, Vanier believes, the more our answers evolve. We begin in fear of their appearance and behavior; move on through pity; pass through the stage where we help them and respect them, but still see them as lesser beings; until finally we ... "discover that, by becoming close to disabled people and entering an authentic relationship with them, they transform us." (p. 284)

The question “Do you consider me human?” is an important one for Brown, as he seeks to determine just what makes someone human and to find a basis for affirming that his son can be seen to fully embody that category.

Vanier elaborates on the “authentic relationship” referenced in the above passage in his book *Becoming Human* (1998). He de-emphasizes intellectual ability—the “mind”—as the only important aspect of humanity, and finds the center of human worth in our ability to relate to and emotionally affect one another. According to Vanier’s assessment, people with intellectual disabilities are “people of the heart” who are capable of entering into meaningful emotional relationships with others (Vanier, p. 2). He refers to such a relationship as one of communion: “Communion is mutual trust, mutual belonging; it is the to-and-fro movement of love between two people where each one gives and each one receives. ... Communion is mutual vulnerability and openness one to the other” (p. 28). Vanier’s description of a “to-and-fro movement of love” where “each one gives and each one receives” echoes the transfer of affect between people posited by both Spinoza and Shouse. For Vanier, this affective transmission is the site of meaning, the proof of humanness on the part of both the disabled and the nondisabled. This echoes, and particularizes, Spinoza’s concern with affect as characterized by Damasio: “Spinoza saw drives, motivations, emotions and feelings—an ensemble Spinoza called affects—as a central aspect of humanity” (Damasio, 2003, p. 8). Vanier affirms the centrality of affect and emphasizes that people with intellectual disabilities are fully able to experience and participate in this aspect of life.

This understanding of affect and emotion is a somewhat different model from the one Brown starts with, which emphasizes the *inner* emotional life, but not so much the *interactive* or *social*. However, as he proceeds through his narrative, Brown continues to circle back to the

ways he is affected by Walker, and the power Walker has to influence those around him. Brown reflects that “on his good days, Walker is proof of what the imperfect and the fragile have to offer; a reminder that there are many ways to be human; a concentrator of joy; an insistent nudge to pay attention to every passing mote of daily life that otherwise slips by uncounted” (p. 180). Brown focuses here on the “imperfect and fragile,” which Vanier would argue includes all humanity, as well as on the emotional effects Walker’s presence often conveys. The relationship Vanier proposes involves the recognition of strengths and weaknesses in all people in order to foster a positive affective space: in the introduction to *Becoming Human* he states, “This book is about the liberation of the human heart from the tentacles of chaos and loneliness... It is a liberation that opens us up and leads us to the discovery of our common humanity” (p. 5).

In spite of his wariness of the religious basis of Vanier’s philosophy, Brown ends his search at a similar ideological place as Vanier, finding that the affective interaction that people with intellectual disabilities are capable of is what makes them human, even if that interaction takes a slightly different shape than most conventional narratives allow for. Piepmeier (2012) suggests that other families of disabled children have similar hopes for recognition of the worth of people with disabilities: “Parents interviewed for *Families Raising Disabled Children*... articulate the importance of interdependence as a human condition, and that it should be recognized as part of what it takes to be a citizen and a full person.” Being fully human, for Vanier, for Brown, and for the parents cited by Piepmeier, means being in affective relationship with one another and recognizing the humanity in others. Though this is often more easily professed than put into action, Brown’s memoir traces his journey toward recognizing the humanity of his son, not only in spite of his difference but because of Walker’s ability to affect and be affected by the people around him. Though Brown acknowledges that the widespread

recognition of the value of people like Walker may still be a long way off, it is a reasonable and worthy goal to work toward. Movement toward making that goal a reality begins with increased awareness of the potential for meaningful affective engagement that the intellectually disabled have to offer.

Conclusion

At the end of his book, Brown has not made any groundbreaking discoveries about the specific thoughts or emotions that Walker experiences but is unable to communicate through speech; nor does he reach any definitive answers about how to understand Walker's worth. However, Brown does make progress toward a broader recognition of the possibilities for human relationship as communicated through affectivity rather than through the intellectual and verbal means so highly valued by society and academia, including the academic field of disability studies. I argue that the trajectory of Brown's personal quest, as I have outlined it here, has important repercussions for the ways that theories of affect and disability studies can be productively brought together to formulate understandings of intersubjective and interdependent affective relationships for people with cognitive disabilities. Recognition of the possibility and power of affective relationships for people whose intellectual, physical, and communicative capacities are in some way different enables new ways of interrogating and understanding the diverse range of human experience.

Brown's characterization of his quest early in the memoir provides insight into the path he follows toward recognizing the power of affectivity in his connection with Walker: "All I really want to know is what goes on inside his off-shaped head, in his jumped-up heart. But every time I ask he persuades me to look into my own" (2009, p. 3). Although this statement might be read as indicating that Walker is merely a vehicle toward Brown's own self-reflection

or self-discovery, I would suggest instead that Brown here emphasizes the affective relationship that he has with his son. In his search to understand Walker's emotional experience, Brown is brought back to his own "heart" through the affective interconnectedness between himself and Walker. At the very end of the book, Brown describes a moment of calm as he holds Walker while his son is having a seizure: "I knew I loved him, and I knew he knew it. I held that sweetness in my arms, and waited for whatever was going to happen next. We did that together" (p. 288). The affective connection with Walker that Brown experiences, through closeness of both mind and body, brings him a sense of peace and communion that transcends differences in ability.

Throughout his memoir, Brown comes to realize that although he may never completely understand what goes on inside Walker's head and heart, that sort of intellectual understanding is not the only way to find value in his son. This realization is significant, both for Brown's own view of disability and of Walker, and for disability studies and its recognition of the rights and values not only of disabled persons who are able to engage in academic and intellectual pursuits, but also those who are not. Normative views of physical and cognitive ability are ongoing challenges both for Brown and in society at large, and I by no means claim that Brown overcomes all of these views during the journey documented in his book. However, his gradual recognition of Walker's affective life is a step toward better understanding of and greater openness toward alternate ways of being human that include living with significant cognitive differences. By identifying the constructive potential of affect in relationships between people with and without cognitive disabilities, Brown's book makes an important contribution to the disability studies project of recognizing those with abilities and disabilities of all kinds as valuable members of society.

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