

BOOK REVIEW

Still Life with June

by Darren Greer

(Toronto: Cormorant, 2003, 335 Pages)

Review by Jihan Abbas

But eventually your humanity, your inherent God-given messiness, will shine through. Only children are exempt from this rule. And children, with the exception of [June] and a few like her, almost always grow up.¹

Still Life with June is the fictional story of a struggling author, Cameron Dodds, and the unraveling mysteries surrounding his life and the people he encounters. Included are: Dagina, a woman from his writers' group; Darrel, a deceased drug addict from the treatment center Cameron works at; and Darrel's estranged sister, June, a woman with Down syndrome now living at the Sisters of Good Hope care facility.

Before going any further in my review of this novel, it is important that I share my personal interest in Down syndrome and its representation in popular culture, as this relationship clearly dominates my reading/review of this piece. As the sibling of a man with Down syndrome I take great interest in the many ways in which Down syndrome is constructed through the arts. I firmly believe that the social constructions of Down syndrome powerfully affect the many ways the non-disabled world has come to know my brother. Indeed, throughout his life I have witnessed countless times and in many different (and often unpleasant) ways how the world relates to him as a result of their limited and/or inaccurate views of what it means to have Down syndrome. As I will argue throughout this review, the characterization of Down syndrome in Still Life with June disturbs me as it reinforces those stereotypes of Down syndrome which have oppressed my brother (and many others) for much of his life.

Many (if not most) readers will likely not be bothered by the stereotypical way that the character, June, is constructed. However, it seems safe to assume that those readers will likely also overlook this representation as their experiences of and with Down syndrome have predominantly been through the arts and media, through works like this novel, which deliver a

portrait of Down syndrome that is neither "new" nor, unfortunately, accurate. For readers familiar with the complex realities of intellectual disability and/or Down syndrome, this novel will likely represent yet another story in which Down syndrome serves as a metaphor for other things – a popular story-telling device that seems to exist in the novel only to provide non-disabled characters with insight and growth.

If you have ever had a child disappointed in you, you'll know how I felt that day. Disappointment in adults can be dismissed easily enough. Adults have an agenda. Adults feign disappointment far too often for us to ever recognize the genuine article in one another, even if it really does exist. But a child's disappointment is pure, complete, and deeply felt. When you have disappointed a child you have a sense you have disappointed God. — The fucking retard.²

For me, the most telling and troubling aspect of *Still Life with June*, and its construction of Down syndrome, is the failure to present June as a unique individual. Throughout the novel, June is presented as no more than a blatant stereotype of Down syndrome – overweight, overjoyed, simple, a holy innocent, slovenly, and unaware of the ways in which the world perceives, and marginalizes, her. There is no indication that June is a real woman, scared and shaped by the difficult life she has led; a life which includes a history of abuse, isolation, and institutionalization. What makes me most uncomfortable about this portrayal is that while marginalizing the character, June, in this way, the author conversely did a phenomenal job of illustrating how all his "Other" and "othered" characters (who were, incidentally, all non-disabled), were shaped and influenced by their pasts. One of the most striking examples for me is that all of these "other" characters in this novel are revealed to be not who they originally seem. Through the course of the novel each one of these characters reveals compelling, vulnerable, and ultimately human characteristics – except for June who remains the simplistic and innocent "Down's girl."

The lack of growth and identity in June is what makes this novel so disappointing for me, especially given my own ways of knowing Down syndrome; ways of knowing which are grounded in my brother and his relationship with the world. Given what the reader learns about June (i.e., that she is orphaned, has a history of abuse, is estranged from her brother, and has been institutionalized in a site with a known history of sexual abuse of its female "patients"), it is incredibly frustrating for me as a sibling/reader that June's character is never given the space to evolve as a real and complex person. Instead, June remains trapped inside the simplistic and isolated

world Greer paints of what it is to have Down syndrome. As a result, June seems to primarily act as a plot device that advances Cameron and Darrel's stories rather than as a real woman shaped by her past and adapting to the world based on her own lived experience.

She's less complicated than most people. And not as stupid as you would think. There are subtleties to her that take some time to figure out, but June will never lie to you, and she'll never betray you. I've found a certain value in that

June will never try to be someone she's not

Exactly... June is always June.³

In addition to my disappointment around June's character and how she was bound by the qualities ascribed to her because of having Down syndrome, I was also incredibly uncomfortable with the use of the term "fucking retard" throughout the novel. Although I realize the use of this language may in fact have much to say about the characterization of the character, Cameron, that Greer was constructing, I can't help but be disturbed by its use, especially given the recent resurgence of the word and the cultural and political backdrop of its renewed use. It seems as though the word is enjoying somewhat of a revival based partly on the premise that "we" (i.e., those occupying traditional places of power and privilege) need to push against the ideology of "politically-correct" language and return to an ideology of "honesty." Without delving too deeply into the politics of language, it would appear safe to say that in the case of the word "retard", this language is not being reclaimed by the group that is both marked and oppressed through its use, but, rather, by those "inconvenienced" by the practice of deconstructing words, their attached meanings, and how their use affects subjugated groups. Indeed, I sensed defiance in its use within the text, as if it was being used to illustrate the ways in which the character, Cameron, operated outside the "norm" and "silly" cultural parameters. Never once did I sense the word was being employed politically to allow the reader to reflect back on June and the restrictions placed on her through the use of this word. In fact, given that June never did develop as a unique individual outside of stereotypical notions of Down syndrome, it is also safe to assume that the use of "retard" in the text was never meant to be reflective of the social and cultural barriers confronting a person with Down syndrome.

Generally, this novel left me frustrated that, once again, Down syndrome was playing out in the typical, simplistic, metaphoric, and narrowly defined

way that I have seen it shaped countless times before in literature. This left me wondering what this novel could have been had June been given the opportunity to develop and grow based on her lived experiences in the same ways that other characters were given the space and depth to do so. I wonder how powerful *Still Life with June* could have been, for me as a sibling/reader, if June was another woman in the novel marked by, and struggling with, all of the experiences she has endured rather than simply a "Down's girl" who operates in the background, untouched by growth or insight. Indeed, had June been constructed as a real, evolving, and interesting character and allowed to grow accordingly, I imagine I would have found myself engaged in a rich and unique text rather than simply another novel that got so much right, yet failed to "get" Down syndrome. I yearn for a novel in which the characterization of Down syndrome is real and complex and which positions Down syndrome as another (valued) human element rather than simply a formulaic backdrop used to advance the awareness of the non-disabled cast. It is truly disappointing that this novel failed to recognize this potential and incorporate it.

References

- ¹ Page 117. Cameron making the realization that "who" we really are will eventually be revealed, except in the case of people like June.
- ² Page 160. Cameron, reacting to June's disappointment with his use of bad language.
- ³ page 248. Cameron, in an exchange with Dagina, explaining his "friendship" with June.

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BOOK REVIEW

Count Us In: Growing Up With Down Syndrome

By Jason Kingsley & Mitchell Levitz
(Florida: Harcourt Brace & Company, 1994, 181 Pages)

Review by Karen Todd

When I found myself unexpectedly pregnant at 42 years of age, I was concerned about the risks of having my first biological child at this stage of my life. Amniocentesis confirmed that my unborn baby was a girl and that she had trisomy 21. My husband and I had 10 days to decide whether or not we would continue our pregnancy. It was an emotional time as we dealt with our grief and disappointment, shared the news with our four sons aged 12 to 28, and tried to learn as much as we could about Down syndrome. Given our age, our primary concern was what would happen to our daughter when we were too old to care for her. She would have four older brothers whom we hoped would share some of the responsibility if need be, but we also didn't think it fair to burden them with the results of our choices.

Books like *Choosing Naia* and *Expecting Adam* were helpful in that they related the experiences of other couples faced with the same decision. They also contained a myriad of resources for parents and teachers on the importance of early intervention programs, learning strategies, health issues, etc. What I didn't find at that time were resources that helped me understand how the world was experienced by a person with Down syndrome - what it would feel like for my daughter. I found what I was looking for just a few weeks ago.

Count Us In is a wonderful book written by two young men, Jason Kingsley and Mitchell Levitz, both with Down syndrome.

Barbara Levitz and Emily Kingsley gave birth to their sons in the early 70s. Both families were told their child would be "mentally retarded" and would never be able to read or write. Emily was told Jason would never have a single meaningful thought or idea and other professionals reinforced this belief suggesting that raising a child with Down syndrome would put tremendous pressure on their marriage and destroy their family. Barbara's doctor said Mitchell's intellectual impairment would be a burden to them. Both families were advised that the common practice was to place these children in an institution right away.

The Levitz and Kingsley families, separately, after much soul searching, decided to take their boys home committed to finding ways to help Mitchell and Jason develop to their fullest potential possible. A relationship between Mitchell and Jason developed because of a relationship that developed between their parents. Barbara and Jack Levitz began the Parent Assistance Committee on Down Syndrome and, three years later, met Emily and Charles Kingsley and their newborn son, Jason. And these relationships continue today, decades after the two families first encountered one another.

When Mitchell and Jason reached adolescence, they became very aware of their disability and felt the need to share their experiences. They talked a lot and Barbara and Emily were struck by the boys' insights and ability to conceptualize the fact they had a disability. Barbara suggested they write a book and the boys were excited about the idea. The moms spent the next three years transcribing discussions between the boys convinced this book would be a forum for sharing insights helpful to people with and without Down syndrome.

The book, in Mitchell's and Jason's own words, and from their perspectives, covers a range of topics including "Girls and Sex", "Politics and World Affairs", "Marriage and Children" and "Becoming Independent." Mitchell and Jason also discuss their appearances on television shows such as *Sesame Street*, *The Fall Guy* and *The Morning Show* with Regis and Kathie Lee, interviews with Jane Pauley, and meetings with U.S. Governors and sports celebrities. At times, the reader needs to work a little to follow the boys' trains of thought but that is part of the book's charm.

While Mitchell and Jason have clearly lead extraordinary lives, one can't help but see the correlation between the level of their development and independence and the opportunities their families sought in an effort to ensure the boys were fully integrated into every aspect of their communities. These families believed that anything was possible and instilled that belief in the boys and in everyone who interacted with them.

Count Us In is an inspirational book for families and friends of people with Down syndrome. Encourage parents to pay close attention to the way in which parents and grandparents interact with the boys – the parenting lessons are implicit. A "must read" for all professionals working with people with developmental disabilities – check your mental models and think about the conversations you are having with your clients. Are your expectations for people with Down syndrome set high enough?

My daughter Meghan is 17 months old. She's crawling properly, is almost walking on her own, and is stringing together several different sounds. I picked up *Count Us In* at this year's Canadian Down Syndrome Society's Annual Convention in Waterloo. After reading this book, and watching many teenagers and young adults with Down syndrome interacting with one another at the Conference, I am excited. Meghan, born 30 years later than Jason and Mitchell, has been welcomed into a world that is so much more accepting of her. Imagine how much more could be possible for her thanks to the work of Mitchell and Jason and their families in helping to educate us on the tremendous learning capabilities of people with Down syndrome.

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