

REVIEWS

A STEP TOWARD FALLING. By CAMMIE MCGOVERN. New York: HarperCollins Children's Books, 2015. **REVIEW AVAILABLE ONLINE @ www.srvip.org**

Reviewed by Emelia Massarelli

CAMMIE MCGOVERN RESIDES in Amherst, Massachusetts, with her husband and three sons; her eldest son is autistic. She has written multiple Young Adult (YA) novels, novels for middle-grade readers, and adult novels featuring young adults with disabilities. Additionally, she is one of the founders of Whole Children/Milestones, a center which serves children and young adults with disabilities. She was inspired to write books depicting young adults with disabilities because of how rarely their stories are portrayed in books and the media. Accordingly, her YA novel "A Step Toward Falling" is a fictional account of the aftermath of a jarring event in which a developmentally disabled girl is attacked. Two of her classmates who saw the attack failed to act. The book offers a poignant portrayal of the conflict that a guilty bystander faces, and the sense of bewilderment of someone who has been seemingly betrayed by society.

The story begins with two high school seniors, Emily and Lucas, attending their first mandatory volunteer service at a learning center for young adults with disabilities. They are both fulfilling their punishment for ignoring a classmate, Belinda, who was being assaulted at a football game. Emily, whose point-of-view contributes to half the novel, cannot comprehend how she got there. As a co-chair of her school's Youth Action Coalition, Emily views herself as an activist and crusader for social rights. Throughout the story, Emily continues to question her own integrity and what type of person she is because she allowed herself to freeze and assume that someone else would save Belinda. While evaluating their true characters,

Emily and Lucas bond during their punishment, and eventually enter into a relationship after discovering that their first impressions of each other were made too hastily. Emily and Lucas come to befriend the students at the learning center and gather the courage to face and apologize to Belinda once she returns to school.

Throughout the story, Belinda faces her own fears about returning to school and interacting with her fellow students. She learns to accept her friend Anthony for all of his quirks and not allow herself to be embarrassed by his antics. A lot of character growth evolves out of the the formation of a four-person production of "Pride and Prejudice" directed by Emily, who partnered with Lucas to create this production. It stars Belinda and Anthony, in honor of Belinda's love for the Colin Firth movie. The resulting performance at the learning center is a modest hit, but most importantly, it proves cathartic and forms a bond among all involved.

At first, I was apprehensive about the voice of the characters, especially Emily. As a high school senior myself, the spunky quips that Emily ripped off in the first chapter of the book seemed forced and unrealistic. However, the author later set a flow of dialogue and consciousness that seemed more genuine. The ability of the reader to relate to the characters' thoughts and actions is critical for YA novels. The nervous self-consciousness that can easily overcome both young people and adults when they are new to conversing with an individual or individuals with disabilities is masterfully demonstrated. Emily's fear of both acting insensitively and overacting with the students at the Lifelong Learning Center is a feeling that I and I know others have had.

While reading this novel, I kept remembering a painful memory from kindergarten that I believe may be relatable for some people. When I was a kindergartener, there was a girl two grades

above me who had Down's Syndrome. At the time I was not familiar with what Down's Syndrome was and had never met anyone with it. My lack of understanding resulted in me being somewhat frightened by this girl, despite my knowing even then that this was not a correct reaction. One day at lunch a fellow classmate saw the girl walk into the cafeteria and said to the table that she scared her and proceeded to duck under the table. Not thinking, I along with my table mates chuckled. The girl never knew this happened, but to this day I still feel ashamed for being afraid of, and mocking, her. Since then, I have met many people, including fellow classmates, with developmental challenges who I am proud to call my friends and who have taught me that fearing someone just because they seem different than you is senseless.

The biggest revelation in the story is Emily and Lucas's realization that there is no need to act any differently around people with disabilities, because that's just what they are: people. After reading this book, I wish that I had been able to read it earlier and would highly recommend it to other young people. It is easy, especially as a teenager, when confronted by awkward or intense social situations to want to pass the burden of interfering to another. Every day in high school you see kids

conform to what their friends and others idealize them as. However, the brave person knows that you must act sometimes despite what repercussions you think could fall on you.

An additional element of the story that was well done was the development of the relationship between Emily and Lucas. While Emily is concerned with treating Belinda as nicely as possible, she sometimes forgets to do the same to Lucas. After overcoming her original judgment of Lucas and entering into a relationship with him, Emily obliviously makes comments that hurt him. However, while preparing for the play, Belinda thoughtfully observes Emily and Lucas's relationship and notices that their dynamic is off. She offers her observations to Emily and clearly makes an impact on Emily's perception of her treatment of Lucas. It's beautiful how Belinda is able to teach Emily something that she herself didn't know. Similarly, McGovern is able to teach us all something that may elude those of us who do not live in close proximity to the disabled.

EMELIA MASSARELLI is a first year student at the University of Virginia & an avid reader. As you may have guessed from her last name, she is indeed related to Jo Massarelli, her loving aunt.

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PIECES OF PURGATORY: MENTAL RETARDATION IN AND OUT OF INSTITUTIONS. By J.D. SMITH. Pacific Grove, CA: Brooks/Cole Publishing, 1995. **REVIEW AVAILABLE ONLINE @ www.srvip.org**

Reviewed by Susan Thomas

THIS BOOK is the author's story of his relationship over several decades with one mentally retarded man, John Lovelace, whose life was first out of, then in, then out of, then back in institutions of various kinds (state mental retardation institution, boarding and nursing homes). These institutions in his later life were located "in the community" and were sometimes even called community services. He had been raised from infancy—but never formally adopted—by a kindly though not very smart couple, who trained him to do various kinds of manual labor; he received very little schooling. The couple apparently were fond of him and wanted to keep him at home, but his turbulent adolescence led them to place him in a state institution, though only for a short time before retrieving him and bringing him back home. However, though he held a regular job in a mill, attended church, and was loved by his foster mother, he was otherwise quite alone, and upon her death, his life went rapidly downhill and eventually he was returned to the institution. The author met him when he was in middle age, and visited and corresponded with him regularly. Then the author took a job in another state, and this reduced the frequency of their contact, though they still saw one other on occasion and still corresponded.

The reason that Mr. Lovelace ended up placed in institutions at various times, and transferred from one to another later in his life, was due to his outbursts of anger, sometimes accompanied by physical aggression against fellow residents. But, the author notes, "John's anger seemed to grow worse with each change of placement" (p. 56), and yet "change of placement" was the in-

variable service response to his anger—truly a vicious cycle of wounding. Placement in one "adult home" was his ninth placement in six years (p. 65). Thus, without using the words, the book is solid documentation of the wounds of physical discontinuity, segregation and congregation, involuntary poverty and its effects, impoverishment of experience, and negative imaging, to mention only some.

Dr. Wolfensberger used to say about war and black markets that cigarettes, coffee and alcohol became the most important commodities. So too, the author reports that "Cigarettes, and, to a lesser degree, coffee, are the currency of adult homes and similar places. People live for them" (p. 68). It was Mr. Lovelace's addiction to tobacco, and his inability to meet his cravings, that so often led to his angry outbursts. After his residence had taken from his government check its monthly charge, the small allowance left each month was not sufficient to provide him the cigarettes he needed to get through the month, let alone to pay for toiletries, clothes, entertainment, or even repairs of his few possessions as well.

Some of the residents of these "adult homes" had no next of kin and no resources to afford even a modest burial. "Cremation is sometimes the least expensive, and, therefore, the most desirable, alternative. The case manager told me of the death of a man whose case she had managed for many years after his discharge from a state institution. When he died, his remains were cremated, and his ashes delivered to her office. Uncertain what to do with them, she put the container on a shelf, where it had been collecting dust for five years" (p. 140). This is a sad example of the results of both involuntary poverty and absence of freely-given relationships, as well as of the role of object or discardable waste.

One of the places Mr. Lovelace lived in his later adulthood, an "adult home," housed 200 residents who were described to the author as "dead-end" people (p. 10), mostly people who were "poor, sick, old, severely handicapped, alone

in life, or some combination thereof.” The place was also described as the “end of the line” for the residents (p. 58).

While the book is the story of only one man, it constitutes documentation of many of the perversions of deinstitutionalization in the 1970s and '80s, and as noted, many of the common wounds of devalued people. For instance, just as with nursing homes, so too with “adult homes,” the grim future anticipated for residents led to active direct deathmaking. “By 1989, conditions in adult homes had also become a national issue. The Government Accounting Office had investigated adult homes in six states, including Virginia,”—the state where Mr. Lovelace lived—“and issued a report that described the horrible conditions found in some of those homes. One home’s administrator had instructed his staff to feed a resident only bread and water and to discontinue his medication. The rationale was that the resident was bedridden and ‘dying anyway’.” (p. 62).

The author had organized a segregated summer camp for handicapped adults each year, and both sad and telling is that he initially became concerned about Mr. Lovelace when one summer, Mr. Lovelace’s folder noted that he had a “Do Not Resuscitate” (DNR) order. The author gives a good summary of why people like Mr. Lovelace would be considered by the medical establishment to not be worth reviving or resuscitating; because he was “not only mentally retarded but also poor and alone in life; he has no advocate to speak for him or to assert his value as a person; and he is likely to be viewed by some as a ‘surplus person,’ a noncontributing member of society.” In other words, he was “expendable” (p. 12).

Also, although the relationship between the author and Mr. Lovelace was not mediated by a Citizen Advocacy office, it constitutes a personal unpaid advocacy engagement of the type that Citizen Advocacy tries to promote, and can also be read as a story of such a type of relationship, including the advocate’s fidelity; the tremendous amount of effort and resources he had

to exert to wring just the smallest benefit out of the service bureaucracy; his own personal kindnesses to Mr. Lovelace; and that without these, Mr. Lovelace might have gone without clothes and sufficient food.

The author apparently came to the same conclusion as Dr. Wolfensberger did, since he wrote “I now advise my students to always have in their lives at least one person they are concerned about to whom they are not related in any way, and with whom they are not paid to be involved. I have come to believe that we all need this kind of relationship” (p. 107).

The word “purgatory” in the title is a reference and homage to Burton Blatt’s *Christmas in Purgatory*, that revealed the atrocious conditions in mental institutions. The author also makes several mentions of normalization, and once cites both Wolfensberger and SRV (p. 118). In fact, there are several instances where the author appears to be citing our own SRV texts, as when he says “A society that worships youth will revile old people. A society obsessed with physical and psychological perfection will seek ways to quarantine the imperfect” (p. ix), and “A culture that overly values youth will devalue people who are considered old. A culture that sets narrow standards of beauty will devalue people considered to be ugly. A culture that worships wealth will devalue those who are poor” (p. 118).

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