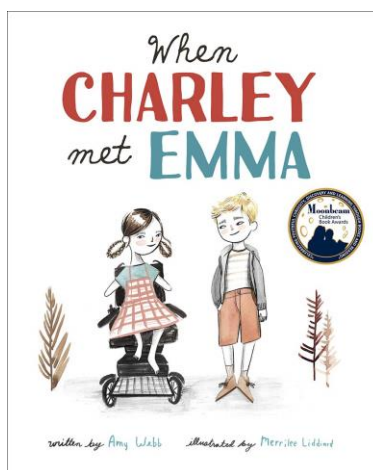


First Opinion: Naming Difference! Now, Name Disability!

Webb, Amy. *When Charley Met Emma*. Illustrated by Merilee Liddiard.
Minneapolis: Beaming Books, 2019. Print.

Emma Fialka-Feldman

Micah Fialka-Feldman



Micah and I grew up in a family where the term “breaking the silence” used by Martin Luther King Jr., was our family’s mantra. My brother, Micah, has an intellectual disability (formerly referred to as Mental Retardation) and has been fully included, with the right supports, in his school and community for over 30 years. He does not read or write in the typical sense. He is different. He has a disability. Learning that “different isn’t weird, sad, bad, or strange. Different is different. And different is OK!” as the author Amy Webb writes in *When Charley Met Emma*, resonated deeply with me. Naming difference and breaking the silence about what is different is part of the work we all must do to celebrate, not shame, difference and disability in our communities. My family didn’t pretend Micah didn’t have a disability. We talk about it often. We talk about the supports it takes to include Micah. We talk about his strengths and his challenges. We talk with him.

When Micah and I were given the invitation to review the book *When Charley Met Emma*, we were excited about the opportunity to provide our reflections as a member of the disability community and as a sibling to my brother. Micah appreciated that the focus was on

Charley, the individual without a disability, and the help he needed to change. Often stories about disability focus on how the person with the disability need help from the community. While support and interdependence aren't bad, it is equally important that characters with disabilities are written in order to highlight the contributions they make. Micah said, "Emma didn't need help. Charley needed help." While we learn about Emma's disability, we also learn about her as a kid.

The story focused on how the mantra taught to Charley by his mother, "Different isn't weird, sad, bad, or strange. Different is different. And different is OK!" was initially forgotten when Charley was at a park and saw another child, Emma, with a physical disability. He said, "Why does she look so weird, Mommy?" His mother appalled at his son's response and his stare, reminded him of what she taught him about difference and encouraged him to introduce himself to Emma. Upon reading the book, Micah said, "Charley's mom gave good help," as often stories can help all the members of the family learn about how to approach difference. In the end, Emma helps remind Charley that difference isn't bad. They learn what they share in common and importantly, they learn what makes them different.

Like Micah, I did not like that the author never used the word disability. While the emphasis on "difference" helped reinforce the author's message that differences are okay, without naming the word disability. Even though the author references, but does not name explicitly, various disabilities including kids who are deaf, blind, or have health impairments, she missed an opportunity to unpack the shame that can be associated with the term disability. It reminded Micah and I of how sometimes people are reluctant to say "disability" and instead say "special needs." Micah confidently says, "I am disabled and proud," echoing the message Emma shares with Charley. The author says, "Emma sat up straight and smiled," highlighting that she is not ashamed to talk about her disability and says, "I was born this way. I have limb differences. That means my arms and legs are different. I can't walk, so I use this wheelchair. I drive it all by myself" (Webb unpagged). If the author had chosen to say, "I am disabled and I was born this way," kids and their families would have received an opportunity to learn that disability is natural and to quote Charley's mom, "...isn't weird, sad, bad, or strange" (Webb unpagged). This was a missed opportunity from the author.

The author's emphasis on Emma's agency in answering Charley's questions the way she wanted to answer them highlights how important teaching self-advocacy skills are. Emma

confidently named what she didn't like that Charley had done (stared) and then answered his questions. Micah said, "It is different meeting a friend you have not met before. It can feel different because you don't know them and might have a lot of questions." It helps younger children learn to name when they see someone who is different and then the author quickly moves children to recognize that having a disability doesn't mean this is one's only identity. Emma and Charley find out what they have in common (being kids, playing tag, swinging, and drawing) and how they approach it differently (Charley uses his hands and Emma uses her foot to draw), and celebrate this.

With few books centering stories of children with disabilities, Micah and I welcomed the intent and delivery of *When Charley Met Emma*. As more stories of children with disabilities are written, we hope authors and illustrators continue to be models of how disability is natural and beautiful. Being disabled can be one part of someone's identity but that alone is not all a person is. Honoring the contributions someone can make with a disability, as Emma shares her passion for drawing, are important ways to break the silence and stigma around disability, not just difference.

About the Authors

Micah Fialka-Feldman is a self-advocate, teaching assistant, outreach coordinator, national speaker, and pioneer who fights for disability-pride, justice, and inclusion. He is part of the first wave of adults with intellectual disabilities who have attended college and has been fully included in school and community. Micah's disability advocacy has a foundation in the creation of the "Beloved Community" and the notion that "A community that excludes even one of its members is not a community at all." Micah earned a certificate in Disability Studies from the Syracuse University School of Education in 2015. Micah currently lives in Syracuse N.Y. where he co-teaches classes in inclusive education and disability studies. He is an outreach coordinator at the Lawrence B. Taishoff Center for Inclusive Higher Education. In May of 2014, Micah was appointed by President Obama to President's Committee for People with Intellectual Disabilities. He is featured in the upcoming documentary by Dan Habib, *Intelligent Lives*.

Emma Fialka-Feldman is an elementary teacher in the Boston Public Schools. She advocates for inclusive schools by working on the Boston Teachers Union Committee fighting for

Inclusion Done Right across the district. Emma has spoken about the topic of inclusive education and nurturing families as advocates for their children, the unique relationship between siblings with and without disabilities, and the importance of progressive individualized education plans in schools.