

What people say about *What Matters: Reflections on Disability, Community and Love*

Janice Fialka has taken up the adventure of parenting bravely, creatively, and mindfully, and here she shares a lifetime's harvest of wisdom and practical guidance for families, educators, clinicians, and all the rest of us. She writes, early on, that "Micah has deepened my understanding of the absolute brilliance of asking for help. He is at ease with what he can do and what supports he needs." This is a counter-cultural brilliance in American life, but with a winsome combination of poetry and pragmatism, she reveals it as possible for us all - and as a beautiful way out of the impoverishing illusions of "self-sufficiency" and "normalcy." I am grateful that this mind-opening, life-altering, soul-stretching book is in the world.

—*Krista Tippett, Executive Creator/Host, On Being + The Civil Conversations Project
Author, Becoming Wise: An Inquiry into the Mystery and Art of Living*

Take into your heart the message embodied in this book and everything else about inclusive education will naturally fall into place. If you read only one book this year, make it this one. It's the real deal.

—*Cheryl M. Jorgensen, PhD, Inclusive Education Consultant*

Wisdom is timeless, but insight may grow over the years. I am grateful to Janice Fialka for taking the time to reflect on the wisdom she gained as Micah's and Emma's mother, and how her insights have grown in 20 years since her first book. Parents of people with developmental disabilities seldom have time to reflect. *What Matters: Reflections on Disability, Community and Love* is a gift to us, a chance to open our hearts and minds to reflect on our own paths, insights, and wisdom. It is a gift to the field, as well, an invitation to think of how much has changed and how our professional allies have helped to open the horizons for all us. We are in this together.

—*Sue Swenson, Acting Assistant Secretary for Special Education and
Rehabilitative Services, US Dept. of Education*

The Fialka-Feldman family has taught me that there can be no inclusion without the inclusion of my son's voice. With Janice's help I have learned that my son's voice is crucial to creating a circle of support. When we listen to him, we learn how to think out of the box; he learns that he belongs at the table both at school and in life. Thank you Fialka-Feldman family for reminding how to listen with love and how to keep dancing when I don't do it so well.

—*Cindy Estrada, Vice President, United Auto Workers (UAW)*

This book offers delight, clarity and insight not only for those seeking inclusion in society, but for all people working to change things that matter to us. Whatever our cause, the questions persist: How do we persevere for the long term without being overtaken by anger and exhaustion? How do we keep improving relationships with everyone, even those bureaucrats and professionals who hide behind their expertise? How do we celebrate and cry together and learn that joy is always available in our deep connectedness, no matter the external circumstances? These questions are answered here, by this persevering, insightful, loving family and their friends.

—*Margaret Wheatley, Best Selling Author, Leadership and the New Science and
other books*

Having a child with a disability makes life busier, more complicated, and much, much more creative. This collection of writings by Janice Fialka, her family, and others captures the evolution of their lives over three decades—lives of adventure, love, laughter and risk taking. With powerful honesty and eloquence, her writing shows us what it means to be fully inclusive, and what it means to be fully human. This collection is an essential toolbox for families and educators who are navigating a world of diverse abilities.

—*Dan Habib, Filmmaker of Including Samuel and an upcoming film featuring Micah Fialka-Feldman*

I have always believed that we are all one another's mentors just as surely as we are all one another's mentees. You will see this principle exemplified in Janice Fialka's life and her work which are inextricably intertwined. She has a way of opening her life experience like a book from which we all can benefit and to which we can be contributors. This is an act of great generosity and humility that she has clearly imparted to her children and they, in turn, to us. We learn from them, both about what inclusion really is and also how to draw on and share one's own experiences as an example. I have no doubt that, as a reader, you will find comfort and insight in the warm company of Janice, Rich, Micah and Emma and their friends as soon as you open these pages.

—*Mark Larson, Ed.D*

The webs we weave in our lives can become complex and difficult, especially for families who experience disability (which, ultimately, is likely to be most of us). Janice Fialka reminds us that if we focus upon what is important – love and laughter, creativity and intention, interdependence and community – we can live incredibly rich lives of joy, celebrate difference and move beyond those societal attitudes that can be disabling.

—*Sharon Lewis, Former Commissioner, Administration on Intellectual and Developmental Disabilities, U.S. Dept of Health and Human Services*

In this book, Janice Fialka invites us to explore and reflect upon, "What Matters." Through poetry, storytelling, and the sharing of life's struggles, she not only opens her heart to the reader, but she allows the reader's heart to open, just a bit more with each page. Her insight, her awareness, and her profound dedication will inspire you to continue to fight for justice, to live with greater compassion, and above all, to work and live from a place of love for one another, regardless of ability!

—*Kristie Pretti-Frontczak, Ph.D.*

I devoured this book in one sitting complete with both laughter and tears. Janice and her family share their stories with an authenticity that is rare but desperately needed in a world that glorifies easy answers, exceptionalism and professional interventions. Through their stories we see that only when we turn towards one another and do what is right, especially when it's hard, do possibilities for a full life truly emerge.

—*Caitlin Petrakis Childs, Community Organizer and Consultant, Former Director of the Real Communities Initiative*

You will notice that all of the contributions from others in this book mention friendship. This is not an accident. Janice has many gifts. But most salient is her authentic and intentional ability to truly connect with people. Janice is eager to know . . . really know . . . YOU. This beautiful give and take is what readers will feel with every entry in this book, old and new. This wonderful compilation invites you into an ongoing conversation about family, disability, hope, and expectation. It asks us to explore important questions about how we can make things better for our families and our communities. This book is a warm hug of encouragement, a shoulder to cry on, a magic mirror that tells each reader in no uncertain terms, “You are not alone!” It will become a touchstone and friend that you can count on for years to come. Just like Janice.

—*Meg Grigal PhD, Co-Director, Think College Research Fellow
Institute for Community Inclusion, University of Massachusetts Boston*

Janice Fialka chronicles her family’s odyssey through challenges and obstacles, false turns and foul winds as they make their way, step by step, with heart and courage and gathering wisdom. *What Matters* is also a reflection on our wild and dazzling diversity, and the universal and irrepressible agency that lives inside every soul, ready to spark up and surprise us if we’re prepared to pay attention, and then fan those first flashes into life-giving fires. This is a book for parents and teachers, lawmakers and policy people, and anyone interested in creating a future fit for all — a place of joy and justice, powered by love.

—*William Ayers, Distinguished Professor of Education (retired), University of Illinois, Best Selling Author, Teaching with Conscience in an Imperfect World*

Nothing sharpens and redefines your priorities as a parent like learning that your child will live with a disability. Typical stresses are quickly forgotten, and new worries can seem insurmountable. In this book of essays, Janice Fialka and her family selflessly offer incredibly honest stories of how they have dealt with the challenges, built the relationships, and shared their successes so others can learn and benefit. Her family is helping other families realize that, disability or not, all of us can have dreams, work hard, learn from failure, and experience sweet success.

—*Beth Swedeen, Executive Director, Wisconsin Board for People with Developmental Disabilities*

Janice and her family have taught me that we all thrive best in the presence of community and that we cannot expect that community to magically emerge out of nowhere. It takes organization. I have watched Janice and her family do this kind of organizing in the disability rights movement since I can remember and it has been a tremendous gift to the way I go through the world. True to form, they found a way to include each voice in their collective story. I am honored to continue to learn from Micah and his family’s journey and am constantly in awe of Janice’s ability to spoon from the softest places of her delicious heart and share the bounty.

—*Julia Putnam, Principal, The James and Grace Lee Boggs School*

As a retired Detroit Public School teacher, Lifelong Learner and Community Educator, I am convinced that this book matters. It provides a needed framework for education that few people understand. The type of learning that combines schooling, family and community education in a substantive manner. *What Matters: Reflections on Disability, Community and Love* will give readers a rare education of a family’s struggles, growth and willingness to be

vulnerable in public about a lifestyle that few people would have the courage, understanding and love for community to share. This book will give new meaning to the word education.

—Kim Sherobbi, Detroit Public School Teacher, retired, Board Member of
James and Grace Lee Boggs Center to Nurture Community Leadership

This book is a treasure. Its stories, essays, and poems guide the reader through a beautiful range of human experiences and feelings, including fear and pride, validation and inspiration, compassion and vulnerability, guilt and dignity, courage and commitment. From page to page, it walks a journey of inclusion, community, and love, inviting the reader to share in the challenges and lessons of this journey. In sharing her and her family's voyage to discover "what matters," Janice Fialka has also given us a clear and compelling way to think about the even more profound question of what it means to be a human being.

—Stephen Ward, Associate Professor, Department of Afroamerican and
African Studies and the Residential College, University of Michigan

Janice is my muse about families and disability over the lifespan—the creative source who inspires my mind, heart, and soul. I experience insight and inspiration from every interaction I have with her. I am indebted to Janice and also to her precious family—Micah, Emma, and Rich—who are her bedrock. If I could recommend a single book about family life and disability to families and professionals alike, hands down it is this one—*What Matters*.

—Ann P. Turnbull, PhD, Distinguished Professor Emerita, Department of Special
Education, Co-Founder, Beach Center on Disability, University of Kansas