



Micah Fialka-Feldman

Foreword

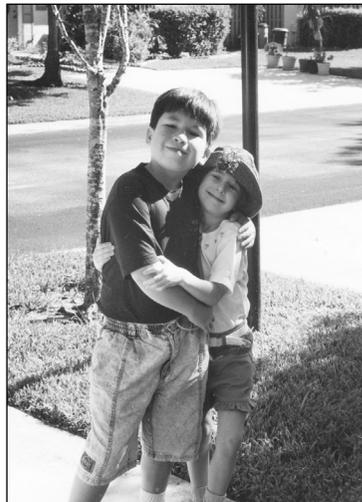
I was 9 years old and my brother Micah was 13 years old when my mother first published *It Matters: Lessons from My Son*. I would often joke (although with some honest envious truth), “What about *Lessons from My Daughter?* I matter too!”

It was 1997. Inclusion was emerging as the way to provide opportunities for all students to learn. The Amendments to the Individuals with Disabilities Education Act (IDEA), signed during this year, reinforced the education of children with disabilities with their nondisabled peers and the importance of setting high expectations for students with disabilities. The historic civil rights legislation guaranteeing protection for people with disabilities, the Americans with Disabilities Act (ADA) of 1990, was just seven years old. Disabilities Studies had recently emerged as a course of academic study at Syracuse University in 1994. As our country’s understanding of disability has evolved, so has our family’s.

In this updated and expanded edition (*What Matters: Reflections on Disability, Community and Love*), you will bear witness to the continued journey of our family and glimpse the journeys of other families. There is no one way to live lives of dignity, determination, dreams, and dance. I know that



Jerome Magid- photo



Micah is who he is because of a continued belief that risk-taking and building community are values that guide us.



Micah with Yoshiko Dart

In 2013, Micah spoke at the White House's 50th Anniversary of the Developmental Disabilities Assistance and Bill of Rights Act event. To honor the 25th Anniversary of the Americans with Disabilities Act (ADA) in 2015, my parents traveled to several cities with the huge hero puppet of Justin Dart, the father of the ADA, participating in marches and public events (<http://www.adalegacy.com/ada25/ada-legacy-tour>). Micah now works as a teaching assistant in the School of Education at Syracuse University. Much has changed since 1997.

I am now an elementary school teacher, teaching students with and without disabilities in my inclusive classroom. This is not easy work. Inclusion is still a practice and philosophy that families must fight for; it is not yet the expectation at schools and within communities. Recently, I had a second-grade student, Kevauna, with Down syndrome. Her family, not unlike my own, moved her from a substantially separate classroom in school to an inclusive setting. They, rightfully so, wanted Kevauna, their daughter and niece, to grow and thrive with her peers in an academically and socially rich environment. They have seen the stories of young



Emma Fialka-Feldman (right) with her student Kevauna (center) and her mother Tamika (left)

adults with intellectual disabilities attending universities; they are beginning to see how high expectations and imagination are part of the conditions necessary to her growth.

As I worked with Kevauna and her family, I took on another identity. I was no longer only the sibling of a brother with an intellectual disability and an advocate for disability justice. I was also a classroom teacher learning about how to make inclusion work. I found ways to meld disability history into my classroom teaching so that my students learned why all children belong in our classroom community. I discovered how many adults are needed to make inclusion work so that children grow socially and academically. I researched reading and math programs so that Kevauna, like her peers, could see herself as a mathematician, a reader, and a writer. I began to deepen my understanding about the other roles in my own brother's journey – the roles of teachers, self-advocates, families, and other service providers.

I have sat with families as they have received the news of their child's label and heard the reading of results from an IQ test. I have nudged and, at times, lovingly pushed families to be fiercer advocates for their children. I have reminded families to pay attention to the unique needs of the other children in their family – those without disabilities. I have connected families with resources that help families see the possibilities for their young child with a disability. This new edition, *What Matters: Reflections on Disability, Community and Love*, continues to be a book that surpasses time.

The stories, poems, and articles enclosed remind us that this work – for parents, family members, siblings, and professionals – is emotional, personal, and probably too often, overwhelmingly challenging. I share these stories with the families and educators with whom I work. May these poems and stories continue to spark discussion, raise expectations of possibilities, and validate emotions.

You are not alone – even if you feel like it. Whatever your

role, you are part of a journey of helping to create a world that works for many with dignity, determination, and dance – for families, for educators, and for individuals with disabilities. This book is no longer a story about Micah, “the son.” *What Matters* now tells the stories of many people in many situations. These are honest stories written about and by Micah, stories about the roles of family members, and stories about the roles of professionals. *What Matters* is about giving dignity and voice to all who have chosen this journey, educators who have sought out this journey, and family members who were born into this remarkable journey. However we come to be on this journey, these articulations give voice to what matters.

Emma Fialka-Feldman
January 2016
<http://emmaff.blogspot.com/>





PREFACE (2016)

It's been almost twenty years (and 9,000 copies) since this little book, *It Matters: Lessons from My Son*, was first published in 1997. I had no intention of writing a book at the time. I was raising two children, directing a teen health center, and speaking on the topics of parenting a child with disabilities and building parent-professional partnerships. It was my husband Rich Feldman who encouraged me – okay, strongly nudged me again and again! – to compile some of the poems and essays scattered across my messy desk into a booklet. He felt that a written component would be an important addition to my work and presentations. Although I initially resisted the idea, he turned out to be right. This collection has “mattered” so much to my journey as a mother, as a social worker, and most importantly as a person finding her way in this gloriously complicated world. The book has sparked others to share their stories of struggle, courage, and hope with me. Countless times it was their stories that sustained me and inspired my next step forward.

A year ago, Rich began persuading me again, this time to expand the book to include newer stories of Micah's journey into high school, college, work, and community living, as well as our family's journey of transformation through the decades. As before, I resisted and resisted until . . . well, here it is.

The new edition with its new title, *What Matters: Reflections on Disability, Community and Love* includes my writings from the 1997 edition, several of my newer published poems and essays, as well as new articles I have written especially for this new edition. I am honored to also include writings by my husband, Rich, our children, Micah and Emma, several interviews, and new articles by several important people from Micah's community in Detroit and Syracuse specifically written for this new edition. My hope is that the book captures how my understanding of what really matters to Micah, our family, and the community at large has deepened.

Micah has consistently shown us what matters to him, beginning early on when he announced (demanded!) in first grade that he no longer wanted to enter his school through a separate door into a self-contained classroom. "I want to go in the same door as all my friends" became our family's North Star. Micah realized his dream to be fully included in K-12 school, with supports. He insisted on being part of the wave of students with intellectual disabilities continuing their education, inclusively, on a college campus. He fought to live in the university dorm, which required a federal lawsuit. He eventually moved to Syracuse, New York – a seven-hour drive from our home – and is now a teaching assistant in the School of Education at Syracuse University. He lives in an apartment with a friend and has community support and a strong circle of friends. He speaks nationally and was recently appointed to the U.S. Presidential Committee for People with Intellectual Disabilities. His life is full. Each of those life events are wonderful for him and for those who he touches. Each has been possible because of Micah's determination, use of technology, enormously rich opportunities, and imaginative

supports from others in his life!

When we ask Micah what really matters to him, he tells us it is having his voice and dreams respected and encouraged. What matters to him is the opportunity to belong and contribute in a variety of communities, to try things out, and to have cable TV!

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.

I love telling the story about one of Micah's first trips traveling by himself (another mother breathless moment!). He was not able to get a direct flight to his destination and thus had to change planes and gates at Chicago's O'Hare Airport – on his own. Micah has hundreds of sight words, but reading complicated signs is not part of his repertoire. With bated breath I waited for a reassuring phone call telling me he had arrived safely to the second gate. Finally, the call came and my breathing resumed! When I asked how he got from one gate to another, in different terminals, his response, tinged with annoyance was, "Mom, I just asked someone for help."

"Of course, Micah! Of course!" Once again he reminded me of how much time I waste "trying not to ask for help!"

The stories behind Micah's hard work and the vital support of his ever-expanding circle of friends are shared in this book, accompanied by the lessons I am still learning along the way.

I am excited to share our daughter Emma's insightful essays in this new edition. As you will observe, she writes with clarity and humor of her varied experiences – as our daughter, as Micah's sister, and now as a dedicated elementary teacher in an inclusive setting. Her stories deeply matter to us and to the many families, professionals, and students who have been touched by her honest, wise, and instructive words and teaching. She has deepened our understanding of parenting, disability, and humanity. I marvel at her ability to dance

with both compassion for others and her strong conviction to demand high expectations for her students, her parents, and her brother. From an early age, she expanded our family's understanding of what mattered to her and ultimately to our family. She noticed when we, as parents, weren't being fair, firmly pointing out to us, "Hey, Micah CAN empty the dishwasher. We BOTH should have chores." She pushed Micah, in a way that only a sibling can, to try new things like learning to tie his shoes or paying the tip at restaurants. Just when we think we've figured out a way to support Micah or to grasp the complexity of a situation, Emma opens doors that we didn't even know existed.

And she makes us laugh out loud, just when we need it! Emma has become one of my best professors and mentors. I can't imagine my life without her "unpacking" of ideas, her diligent questioning, and her "love you mom" in my life.

For me, this collection of essays, articles, and poems is also another step in my own personal journey that began in a loving family in Flint, Michigan, in the 1950s. As a child, the values of caring for others and being curious and compassionate were strongly instilled in me by both my parents, especially my mother, who as a nurse worked with families with disabilities. Her storytelling at our kitchen table always communicated respect and high expectations for the children and families she met. Later in college in the late 1960s and 70s, I was fortunate to be active in the peace movement and the women's movement. From both movements, I learned the power of bold advocacy, the necessity of community, the insistence on justice for all, and the belief that the "personal is political." I took to heart the words of poet Marge Piercy whose poem "To Be of Use" was a guiding prayer for me. I fell in love with my husband for many reasons, certainly his sense of humor, and also because he is driven to make this world a better place. He is committed to visionary organizing and since the 60s has never lost his passion or purpose.

My professional training and work as a social worker reinforced my belief that building and sustaining relationships and making critical connections are the most important aspects of all work. I grew to understand that feelings, the messy ones, the piercing ones, the “facedown on the floor” ones, and the joyful ones are fundamental to our humanity and deserve our close attention and our validation.

I also realize daily how hard it is to truly listen, to truly be present with the other. I cling to the sage advice of Jane Wagner, who said, “Listen with an intensity that most people save for talking.”

My struggles with uncertainty, self-doubt, and vulnerability knock me down often, but on my good days, I have learned to see them as windows to others who experience the same “knocking down” moments.

After 30 years as a mother and an even longer time as a social worker and human being, I am getting closer to a more enlightened understanding of what really matters. While Micah’s accomplishments may appear tall in the stories, he and the disability community in particular have patiently taught me the true meaning of triumphs.

What matters is advocating relentlessly for what we believe in. It’s listening to our children’s dreams and keeping the conversation going as they change and evolve. It’s seeking the support of others and offering support when needed. It’s forgiving ourselves for pushing too hard – or not hard enough. It’s about presuming possibilities and taking risks (even when it keeps us up at night). It’s about having massive patience. It’s redefining disability, not as a deficiency but as a difference, a natural part of the human condition, an imaginative way to live. It’s redefining success and expanding our understanding of what it means to be human and proud.

As Micah taught me in the “airport story,” what matters is

getting from one scary, unfamiliar gate to the next – not alone, but with others nearby. It's about knowing that there is not one way to live, walk, roll, see, move, hear, do, and be. It's about having the opportunity to fly – in an airport or toward our dreams – dreams that matter.

Janice Fialka
March 2016

*Unless otherwise credited, essays, articles,
and poems without bylines were written by me.*

PREFACE (1997)

One night in 1988, unable to sleep, I took my familiar yellow pad of paper, huddled in the corner of the couch, and wrote. I had a lot to say. Earlier that day my husband Rich and I had participated in a difficult meeting about our four-year-old son, Micah. His neurologist, occupational and physical therapists, speech therapist and others had sat with us at an immense wooden table, the kind I imagined King Arthur and his soldiers would have gathered around.

We all had known Micah's development was delayed, but at this meeting Rich and I formally learned that this was more than a temporary condition. His disabilities were significant and permanent. We left the meeting, descended the clinic stairs, walked to our car, and sobbed.

Although my cascade of tears had slowed late that night, I had a million rushing thoughts and feelings. It was soothing for me to pull the words out of my head and push them onto the yellow paper. That night I wrote "Advice to Professionals Who Must Conference Cases," one of the poems included in this booklet. The poem tells about my desire to have the well-intentioned professionals who were in attendance at this meeting do more than give a well-formulated clinical report. I needed them

to be with me as a mother who was scared and grieving.

This one poem has opened many doors for me. It has traveled across the continent through newsletters, professional journals, textbooks. But most importantly its journey has been person-to-person. As a result of this poem I have had the good fortune to talk with deeply caring parents and professionals who have moved me through their stories of courage and compassion.

The first two poems in this booklet, “It Matters” and “For Pam,” tell pieces of the stories of two strong mothers who fought hard to ensure that their children received what they needed.

“You Can Make A Difference in Our Lives” and “Feelings: The ‘F-Word’ in Parent-Professional Partnerships” both offer insights and suggestions to professionals who work with families and their children with disabilities. My parent voice is prominent in these two articles. I also draw on my personal experience as a veteran social worker of twenty years. Being Micah’s mom has helped me to be a more sensitive social worker, especially to the subtle aspects of life-changing news. I have tried to weave both voices into these articles.

“A Hero’s Poem: For Those Giving Life-Changing News” is a small tribute to the many professionals—educators, therapists, consultants, psychologists, physicians, and so on—who have fallen in love with Micah and other children like him, and who have worked tirelessly to create opportunities so all children can reach their potential. We need to say “thank you” more often to these dedicated people.

I have also included a journal entry about my experience as Emma’s mother. Emma is Micah’s younger sister by four years. She has brought balance and joy to our family. She astonishes us daily with her insights and wit. “*When a Sibling Asks the Tough Questions*” describes how I handled her first direct inquiry about Micah’s differences.

The final poem, “The Gift of Support Groups,” was literally written while driving home from a support group for parents of children with disabilities. I was bursting with energy as I felt the connection with people who understood me completely—who had “been there, done that” and who were helping me bolster my inner strength.

Just before taking this booklet to the printer I asked a new friend and colleague, Ann Herrold, to read my selections. I asked her for honest feedback. We hadn’t shared many details about our lives, but I felt a sense of trust in her. As anticipated, she gave me excellent suggestions. Then she offered her story, “Chucky,” about her 40-year-old brother-in-law who is developmentally disabled. When my husband and I read her story we sobbed—again! I knew that she had given me the perfect ending for this booklet. Hers is a story of love and hope.

I am blessed to be Micah and Emma’s mom. Because of them and my husband, I am learning to live my own story of love and hope.

Janice Fialka
October 1997

