



---

## NEA Educator's Book Club for Disability Rights & Inclusion

---

We need champions for disability rights and inclusion! NEA members have a unique and powerful opportunity to advocate for meaningful change, challenge ableism and biases, and become allies with and for individuals with disabilities.

[Find out more about becoming a champion for disability rights and inclusion.](#)

### Who can participate in the NEA Book Club?

The NEA Book Club is open to all members! This is a great opportunity for you to take what you learn and share key concepts with your community.

### How does the NEA Book Club work?

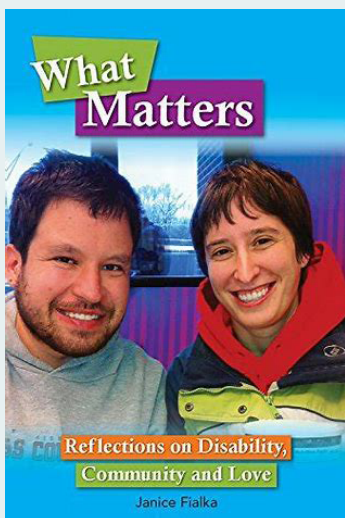
We encourage you to participate in all three book discussions; however, we understand that this may not be possible for everyone. The books that were selected are meant to be read sequentially OR individually. We believe that participants will gain a great deal of knowledge related to disability and its intersections that can be taken back into learning environments and applied in each of our daily lives.

### Where, when, and how will the NEA Book Club meet?

The NEA Book Club will meet virtually three times for each book over the course of the 2023–2024 school year. For those who cannot join the book club, we encourage you to read the books and use the accompanying reading guides to heighten your understanding.

[Learn more about the NEA Book Club for Disability Rights and Inclusion.](#)

## A Book Study in Collaboration with Rebecca Schulz and Emily Nusbaum



### What Matters: Reflections on Disability, Community, and Love

By Janice Fialka

The third book that we will read as part of the NEA Book Club is *What Matters: Reflections on Disability, Community, and Love*. It is an important and moving collection of essays, articles, and poem's about the author's children, her family's experiences, and members of her community who support her family's quest for meaningful inclusion for her son, Micah Fialka-Feldman. This is the story of Micah, who has an intellectual disability, and his ground-breaking journey to full inclusion in K–12 schools, college, work, and life. This collection is a practical guide for families, self-advocates, and professionals on how "to honor interdependency, redefine disability, cultivate relationships, and live a meaningful life."

---

## Reading Guide

### *What Matters: Reflections on Disability, Community, and Love*

#### **What NEA Leadership Competencies are addressed through this book?**

You will gain a foundational understanding of advocacy, communication, leading our profession, organizing, and social-emotional learning. [Find out more about NEA Leadership Competencies.](#)

#### **What are the main objectives?**

From a young age, Micah demanded “I want to go in the same door as my friends” (pg. 13). As a first-grader, he does not understand why he has to go to a different classroom. Micah begins asking questions—like why he needs a separate entrance and classroom in his elementary school and why he cannot live in the dorms at college—which begins his powerful journey of advocating for himself.

Over the course of his life, Micah has built the support team he needs and continues evolving the circle of support around him. As you read this book, you will be exposed to various perspectives about the struggle for disability rights and inclusion. We encourage you to think about what happens in your own school buildings (for example, where are certain students educated and why don’t all students have the same access?); what needs to change in your schools (for example, policies, practices, structures, and expectations); and ways in which we can “redefine disability not as a deficiency but as a difference” (pg. 16). As you read, think about ways that each of us can advocate for the changes essential for growth.

#### **Session 1: Chapters “Forward” Through “Reflections on the IEP Process and Special Education Meetings,” pgs. 9–105 (to be read prior to the first book club meeting)**

---

#### **Pre-Reading Reflection Questions**

1. How do you define “inclusion”? How do you create a world where true inclusion happens?
2. How do you teach and help students learn to advocate for themselves?

#### **Post-Reading Reflection Questions**

1. What do you need to change to create a positive parent-professional relationship when families ask hard questions or do not agree with education team members’ ideas?
2. How do you set high expectations for students who learn differently, especially those with complex support needs or who live within multiple marginalized identities?
3. What resonated most with you in these chapters and why?

---

## Discussion Questions

1. How do we help students to create circles of support outside of IEP teams?
2. What do we need to do and think about differently for this to happen? Why is it critical to change how we define “disability” and in what ways could this change education policies, practices, and structures?
3. How do we create transitions and include what a child needs to grow using honest conversations about their life and IEP goals and involve the students and team members?
4. What did you learn from these chapters?

## Next Steps

Read chapters “College in Michigan” through “Living and Working in Syracuse,” pgs. 109–177, before the next meeting.

## Session 2: Chapters “College in Michigan” Through “Working in Syracuse,” pgs. 109–177

---

### Pre-Reading Reflection Questions

1. Why should you raise expectations for all students and create pathways for all students to learn?
2. How do you participate in IEPs and support youth to plan for their future (for example, authentically learning about student/family desires and dreams)?

### Post-Reading Reflection Questions

1. How do you create accessible learning environments for all students? What are ways that your learning environment might be inaccessible?
2. How do you respond and advocate for change related to segregated special education settings in your role as educator, counselor, administrator, or staff?

## Discussion Questions

1. What are ways we can reduce jargon talk as well as goal-only IEPs to be more inclusive of the family and their concerns?
2. How do we create a culture where people “understand disability not as a deficiency or misfortune but as a difference and unique experience” (pg. 136)?
3. When and how do we begin conversations with a student and their family about their postsecondary dreams and creating a life of community/interdependence as well as independence?

## Next Steps

Read chapters “Family Interview” through “Disability Pride Emerges,” pgs. 180–232, before the next meeting.

---

## Session 3: Chapters “Family Interview” Through “Disability Pride Emerges,” pgs. 180–232

---

### Pre-Reading Reflection Question

1. What challenges do you face in attempting to create a more inclusive setting? What changes do you need to make?

### Post-Reading Reflection Questions

1. “Inclusion is only true inclusion, where every aspect of the person is included vs. who we feel they should be” (pg. 181). How will you transform your own inclusion beliefs where every aspect of the person is fully embraced?
2. What are specific actions that you can articulate in the education setting where you work or in your own life?

### Discussion Questions

1. What are you doing to make sure we are authentically including the perspectives, concerns, and desires of parents/families and students with new insight from Micah’s disability experience?
2. What are ways we can work to dismantle the educational and often adult-life segregation of people labeled with intellectual disability and those with complex support needs?
3. What are ways we can work differently to support each of our students in creating a life of community, especially for those who do not have a robust circle of support?

### Next Steps

Recommend the book to others in your community and have conversations about what you learned.