



Lydia Ocasio-Stoutenburg
and Yuchen Yang (eds.)

LOVE IS PRAXIS

Lived Experience-to-Classroom Lessons
Through the Voices of Disabled
Students, Practitioners, Mothers,
and Siblings

Disability Studies

Collection Editors

DAMIAN MELLIFONT

&

JENNIFER SMITH-MERRY

LIVED PLACES
PUBLISHING



LOVE IS PRAXIS

Lydia Ocasio-Stoutenburg and
Yuchen Yang (eds.)

LOVE IS PRAXIS

Lived Experience-to-
Classroom Lessons Through
the Voices of Disabled
Students, Practitioners,
Mothers, and Siblings

The Disability Studies Collection

Collection Editors

Damian Mellifont &
Jennifer Smith-Merry



First published in 2024 by Lived Places Publishing

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without prior permission in writing from the publisher.

No part of this book may be used or reproduced in any manner for the purpose of training artificial intelligence technologies or systems. In accordance with Article 4(3) of the Digital Single Market Directive 2019/790, Lived Places Publishing expressly reserves this work from the text and data mining exception.

The authors and editors have made every effort to ensure the accuracy of information contained in this publication, but assume no responsibility for any errors, inaccuracies, inconsistencies and omissions. Likewise, every effort has been made to contact copyright holders. If any copyright material has been reproduced unwittingly and without permission the Publisher will gladly receive information enabling them to rectify any error or omission in subsequent editions.

Copyright © 2024 Lived Places Publishing

British Library Cataloguing in Publication Data

A CIP record for this book is available from the British Library

ISBN: 9781916985063 (pbk)

ISBN: 9781916985070 (ePDF)

ISBN: 9781916985087 (ePUB)

The right of Lydia Ocasio-Stoutenburg and Yuchen Yang to be identified as the Volume Editors of this work has been asserted by them in accordance with the Copyright, Design and Patents Act 1988.

Cover design by Fiachra McCarthy

Book design by Rachel Trolove of Twin Trail Design

Typeset by Newgen Publishing UK

Lived Places Publishing

Long Island

New York 11789

www.livedplacespublishing.com

I dedicate this chapter to the students and individuals who find reflections of their own experiences within my story. In moments when support seems rare and mentors are inaccessible, always remember that you are your own greatest source of inspiration. Above all, my heartfelt dedication goes to my parents, who fought for our family, and to my sister, who would fight to whatever end.

—Aimee

To my chosen family, the Kosko-Blyler family, my college professors, and all the other individuals who have touched my life. I wouldn't have gotten this far without you all.

—Ava

To every learner who has ever experienced being an outsider in a place that ought to feel like home—I dedicate this chapter to you. May our schools one day become a site of safety.

—Azaria

To my brother. My life revolves around you, and my heart will always be yours.

—Bianca

I dedicate this chapter to anyone who resonates with my story. Know you are not alone, and your courage is remarkable. And to my family, especially my sister. You are the reason for everything I am and everything I will become. Kerri, you are my “why” forever and always.

—Courtney

This chapter is dedicated to all of the beautiful and courageous children and their families who welcomed me as a member of their support teams. I will forever cherish all of the ups and downs we worked through together.

—Dana

This chapter is dedicated to my younger self. To the person who went through countless years of pain and to the person who thought she was the problem. My experiences have inspired me to fight harder to be better. This is also a reflection of things I went through and gratitude for those in my life.

—Jenna

To my family. I could not have done this without you, and this is all for you.

—Julia

This is for all those who have guided me with their remarkable strength. Particularly, to the exceptional individuals with disabilities that I have had the privilege to cross paths with; thank you for imparting meaningful insights on empathy, insightfulness, and boundless capabilities present in each one of us.

—Karla

I dedicate this book to my family. And to the authors of the chapters in this book and their families, whose stories, courage, resilience, tears, and dreams fill the pages of this book. I am grateful for each and every one of you.

—Lydia

To Sage, thank you for always choosing one more day. To CEM, SGM, and NLM. You make me a better person, and I'm so proud to be your Mamí. To my mom and dad cheering me on in heaven, I love you and miss you so much. To everyone who has supported me and helped me learn and grow... Thank you.

—Millie

To all the women with disabilities who never stop fighting for their rights.

—Nayma

To my big brother, Ian Zinn, who inspires me and challenges me to be a better and more compassionate person every day.

—Rebecca

To the amazing young man who made me a mama, and the eight beautiful loves who came after. To my beloved abuelita Lola who showed me the meaning of true love.

—Ruby

To those who give voice to the voiceless and strength to the struggle, the special education professionals and family advocates, this dedication is for you. Your compassion and dedication light the way for others.

—Yuchen

Abstract

Disabled people, their caregivers, and family members are often on the receiving end of decisions by service providers and professionals. Family members are often positioned as inexperienced in relationships with school professionals, which often carries over into how disabled students are perceived, as well as the opportunities provided for them. These experiences are not uncommon, and can transcend from early intervention to the higher educational context. This book captures the stories of students with disabilities, siblings, practitioners, and caregivers who describe their own ways of knowing, theorizing, identity affirmations, and life navigation, within the school context. Drawing from bell hooks' framing of love as praxis, the authors challenge us to reimagine the classroom as a transformative space. In doing so, we can reposition people across disability, racialized and social identity, familial, cultural, and multiply marginalized lived experiences as experts in their own lives.

Keywords

caregivers, culture, disability, education, family, intersectionality, lived experience, love, practitioner, students

Contents

Foreword: What's Love Got to Do with It?	xi
<i>Beth Harry</i>	
A Note on Language	xvi
Content Warning	xvii
Introduction	xviii
Learning Objectives	xxiii
Chapter 1 A Parent's Fight: Nurturing Identity, Overcoming Adversity	1
<i>Aimee Granada-Jeronimo</i>	
Chapter 2 Older-Younger Sister: The Unknown Middle Child	9
<i>Rebecca Zinn</i>	
Chapter 3 Mama Bear	29
<i>Millie Rodríguez</i>	
Chapter 4 It's Complicated	49
<i>Dana Patenaude</i>	
Chapter 5 Too Much...Not Enough	69
<i>Julia Sledz</i>	
Chapter 6 Speaking Out: A Letter to the Reader	73
<i>Karla Patricia Armendariz</i>	

Chapter 7	“Listen” <i>Bianca Emma Stoutenburg</i>	89
Chapter 8	How Does It Feel to Be a Woman with a Disability in a Developing Country? <i>Nayma Sultana Mim</i>	99
Chapter 9	Finding Myself through Autism <i>Ava Herr</i>	111
Chapter 10	School as a Site of Resistance: Becoming an Advocate <i>Azaria Cunningham</i>	135
Chapter 11	Empowering Exceptionality: A Mother’s Call for Collaborative Understanding in Education <i>Ruby Humphris</i>	145
Chapter 12	Kerri’s Way: Family, Lessons, and Memoir <i>Courtney Kehoe</i>	155
Chapter 13	The System Failed Me, but I Did Not Personally Fail <i>Jenna Spencer</i>	165
Notes		192
References		194
Notes on Contributors		199
Index		205

Foreword

What's Love Got to Do with It?

The narratives in this book argue that love has everything to do with education. But where would we go for guidance on how to infuse love into a special education system driven by legalistic and bureaucratic structures? In the introduction to the book, the author states that our educational system has traditionally been framed as “passionless and objective, without care”. While many may disagree, claiming that school personnel do care about their students, I believe that thoughtful reflection on the way education professionals are trained does support this view. My guess is that a qualitative analysis of the goals of most teacher preparation manuals, and even research reports in leading professional journals of education, would reveal a great deal more about strategies, goals, assessment, and lesson planning than about caring, feeling, or bonding between teachers and their students.

Moreover, I think it is true to say that professional training typically advises budding teachers and therapists not to become “too involved” with their students. The purpose of this approach is to be able to maintain an objective understanding of students’ strengths and limitations. By this view, the setting of personal boundaries is an essential part of professional work, establishing what we believe is a clear line between objective and subjective knowledge. The latter is generally assumed to be less reliable and

less valid. This principle may well hold in relation to the generalized knowledge gleaned from studies of large groups, but it can only be a starting point when working with an individual. At the individual level, we are faced with a whole person whose lived experience presents us with endless contradictions and conundrums that may defy our professional preparation. Listening and watching with love provides the way through this.

This is not to say that we can ignore the difference between a professional and a personal relationship. How do we achieve the needed balance? This book utilizes a range of lenses for viewing this challenge. Through the eyes of siblings, parents, teachers, paraprofessionals, and self-advocates, we become immersed in the highly nuanced and unpredictable ways in which our work can be informed and, indeed, transformed by love.

For example, in Chapter 4, "It's Complicated", the author offers a detailed chronology of her experience of "highs and lows" with a family with whom she formed a strong relationship over several years, but which ultimately ended when it became evident that the services she and her colleagues could offer were no longer adequate for the child and family. The narrative hints at the challenge of becoming so committed to a child and family that the inevitable leaving of that relationship becomes problematic. The delicate balance needed here quivers in the background of this narrative, yet the author concludes that the rewards of work that is informed by love make it all worthwhile.

In Chapter 7, "Listen", a sibling of a boy with Down Syndrome describes how the power of love provides a kind of in-depth,

totally subjectively acquired knowledge of the needs of a child who is nonspeaking:

We use the alternative and augmentative (AAC) device to help him express his needs and wants, but a part of me hoped that he wouldn't have to talk through a tablet. So much can be lost through translation, such as if he so happened to change his mind in a split second on whether he wants cookies and cream ice cream or an ice cream sandwich. And I wouldn't know, because I was too busy looking into the freezer to notice that his facial expressions have changed, and he's signaling me to pay attention to him.

But the lens provided by siblings is by no means monolithic. The author quoted above teaches us about the power of a sibling's bond to read the unspoken communications of a loved one, while also straddling the intersections of her brother's disability and Black identity. Here, the author reflects on how the intersection of racism and ableism often intensifies the social negativity of which her brother, in his innocence, is unaware. The author of Chapter 2, "Older-Younger Sister: The Unknown Middle Child", reveals yet another dilemma as she struggles to find a balance between being the younger and yet the more competent sibling. She details her efforts to develop the self-conscious learning needed to find her footing in a family structure that defies stereotypical expectations and roles.

The lenses of mothers provide us with numerous lessons on the power of parental advocacy. We become aware of how easily professionals can slip into a "we-they" relationship with parents,

closing ranks with colleagues in order to protect our professional status. Instead, we need to ask ourselves the following questions: In excluding or dismissing parents' views, is it my goal to enhance the student's development, or is it a self-defensive reflex intended to fend off demands that I fear might tax my energy or test the boundaries I've established between myself and those advocating for something new for a child? Are my decisions driven by bureaucratic guidelines by which the checking of a required box allows me to believe my job is complete? Or are they guided by responsiveness to information being provided by someone who loves and knows the child way more than I ever will?

With regard to the importance of love in learning from individuals with disabilities themselves, a key issue is the self-image being developed by the individual. These narratives point to the tension between one's intuitive knowledge of oneself and the internalizing of the negative views others hold of us. We see the importance of external supports that nurture self-confidence and a positive self-image. Children learn not only by cookie-cutter positive reinforcers, but by a touch, a look, or a hug that conveys love and approval to a child who might be receiving rejection and humiliation from a cruel and uncaring world.

So, back to my opening question: Where would we go for guidance? I suggest that we turn to the dynamic process of Cultural Reciprocity developed by Kalyanpur and Harry (2012), which calls for us to learn from others whose familial and cultural practices differ from professional expectations. In this approach, we begin by developing within ourselves a sharp awareness of any biases and assumptions that may hinder our ability to listen to and

respect views and experiences that differ from ours. Putting our biases on hold, we can listen to the voices of those who know and love the child, respectfully acknowledging their perspectives. We then reciprocate by sharing our professional understandings and goals, so that both sets of perspectives are respected and taken into account in a process of collaborative decision-making. Thus, love and professional knowledge go hand in hand, thus creating a praxis tailored to the context of an individual's real and daily life.

My last word to teachers in training would be: Do not be afraid to learn from love and to love your students. Your professional training will be enhanced and will still be there to help you keep your balance.

Beth Harry, PhD

Professor Emerita

University of Miami

A Note on Language

This book contains terminology that may not be universally sound, with meaning that is bound to the historical, legal, or contemporary context. In addition, some of the terminology may be archaic and/or offensive to some communities that are shifting away from the negative and deficit-based connotations of the terms. One example is special education, which in the US represents a set of services and supports that serve disabled children there, while also encompassing a set of protective laws. Many disability rights groups and organizations are moving away from the word “special” which has often been used to discriminate against disabled people. Another such term is “disabled”—while in some contexts, person-first language is preferred, in others, identity-first language, such as “autistic person”, is preferred. With that said, we make no claim that language is neutral, for it is situated and constructed around norms that change over time and context. Instead, we note that each of the authors has questioned, troubled, decided upon, or resisted many of the terms, some of which may be placed in quotations to illustrate how the author pushes back on the term.

Content Warning

This book contains explicit references to, and descriptions of, situations that may cause distress. This includes references to and descriptions of the following:

- Suicidal thoughts, intentions, and actions
- Eating disorder behaviors
- Psychiatric inpatient centers and experiences
- Graphic descriptions of acute physical or psychological health crises
- Grief and loss
- Trauma
- Violent assault, sexual violence, and bullying
- Ableism, racism, discrimination, and microaggressions
- Applied Behavioral Analysis (ABA) (although the term in particular, and the field in general, is not universally a cause of distress, some people may have had harmful experiences where any mention of these may cause distressing memories to resurface).

Introduction

When bell hooks spoke about love, it was as if it were the most radical notion. Love, through its energy, power, and insistence, is rarely perceived as a praxis, that is, the theoretical and abstract put into practice. In discussions about teaching, hooks centered love, a positioning that runs countercultural to the framing of most of our educational system, which is often viewed as passionless and objective, and without care. Instead, hooks (1994) redefined love as a “core foundation” and one that “humanizes” (p. 131). The classroom is not a place devoid of emotion or even conflict, for that matter, as hooks described the importance of weaving in elements of care even for moving through points of pain. Hooks added so powerfully, “we bring to the classroom settings our unresolved fears and anxieties...the loving classroom is one in which students are taught both by the presence and practice of the teacher, that critical exchange that can take place without diminishing anyone’s spirit, that conflict that can be resolved constructively” (p. 135).

We think about “conflict” as it has occurred throughout our lives, in our classrooms, in our communities, and through the injustices we feel for people who are most marginalized in the school systems. The conflict is historical, where people with disabilities, their caregivers, People of Color with disabilities, and people experiencing multiple marginalizations have been harmed. Schools have also been complicit in that harm. Disabled people, their caregivers, and even their providers are often positioned as

inexpert receivers of information instead of being perceived as constructors of knowledge who bring rich perspectives into the classroom context.

Through personal narratives and critical ethnography, this book is a portraiture of disability and love through the lived experiences of disabled young adults, practitioners, emerging professionals, and family members. Drawing from bell hooks' centering of love as transformative praxis, it includes testimonies of people whose lived experience repositions them as knowledge-bearers, even when their ways of knowing, learning, practicing, and valuing have been discounted by those around them. Each story introduces their lives in time and context, valuing them as educators who teach others, both informally and formally. This book is a harmony of generational, familial, collegial, and cultural expressions of love.

You'll notice that there is an interwoven structure of the book, from the personal disability narrative to the practitioner lens, from the sibling's devotion to a mother's love. This tapestry of stories provides a rich and deep introspection that underscores how important it is to value all forms of wisdom. Embedded in the chapter texts are elements of storytelling, global perspectives, poetic cadences, and freewriting. The authors are pre-service educators, emerging research scholars, practitioners, and some who share more than one of these identities. There are stories of pain, memory, hope, frustration, and calls for justice. Undeniably, at the center, is love.

Chapter 1, "A Parent's Fight: Nurturing Identity, Overcoming Adversity", describes Aimee Granada-Jeronimo's experiences

growing up in an environment where teachers failed to support and understand her disability. Despite how disability, cultural, and familial biases manifested in difficult school experiences for her, she pursues her goal of becoming a supportive special education classroom teacher. Chapter 2, “Older-Younger Sister: The Unknown Middle Child”, with its story and meaningful title crafted by Rebecca Zinn, discusses the ways in which the author challenges community (mis)perceptions of disability while navigating the world with her brother who has autism.

We move out to the family level in “Mama Bear”, Chapter 3, in which Millie Rodríguez details her battle as a mother of a twice-exceptional child, fighting for her child to be supported in K-12 and transitioning into the higher education context. Emphasizing the need for caring and empathetic practitioners, Dana Patenaude highlights the interdependent and complex relationship with families in Chapter 4 titled “It’s Complicated”. We revisit the personal disability narrative in Julia Sledz’s “Too Much...Not Enough”, Chapter 5, which outlines practitioners’ dismissals of the lived experience of disabled people, emphasizing how even with the complexity of issues, a transformed system is needed, where the status quo is never enough. In Chapter 6, “Speaking Out: A Letter to the Reader”, Karla Patricia Armendariz describes the importance of child and family voice that acknowledges systemic issues from the practitioner’s view while advocating for change. In “Listen”, Chapter 7, Bianca Emma Stoutenburg traces her painful, real, and loving journey as a sister of someone with a disability. She describes the tensions of her prayers for her brother while recognizing the need to advocate for him, which involves a simple choice that prioritizes listening and love.

Chapter 8, "How Does It Feel to Be a Woman with a Disability in a Developing Country?" by Nayma Sultana Mim, provides a rich, intersectional, global perspective that builds upon the theme of practitioner reflection, while also advocating for future policy directions. Ava Herr's "Finding Myself through Autism", Chapter 9, draws the reader back into the closer, more intimate point of view with the personal experience of disability, sibling bonding, and personal growth as a future special educator. In Chapter 10, "School as a Site of Resistance: Becoming an Advocate", a former schoolteacher and emerging education scholar Azaria Cunningham builds upon the theme of pre-service teachers acknowledging the system level and interpersonal biases in education. She achieves this by raising her voice and using poetry to describe/impact a flawed system through advocacy.

Revisiting a mother's perspective in Chapter 11, Ruby Humphris' "Empowering Exceptionality: A Mother's Call for Collaborative Understanding in Education" describes her own journey from her son's diagnosis to advocating for appropriate school support, while also challenging professionals to shift from their deficit views through advocacy. "Kerri's Way: Family, Lessons, and Memoir" by Courtney Kehoe (Chapter 12) takes the reader back to the sibling perspective. Filled with emotions and professional aspirations, the chapter conveys hope. Finally, we round out our chapters with a powerful story by Jenna Spencer in Chapter 13 titled "The System Failed Me, but I Did Not Personally Fail". This chapter echoes the presence of systemic failures found in the prior testimonials, describing how pervasive it is across systems. Jenna's story highlights a journey of

self-advocacy, resilience, personal growth, and empowerment through narrative storytelling.

With each author providing reflection questions for the reader, this book is for emerging teachers as well as those providing both general education and special education services. The book is also for other education personnel, which include not only para-professionals, staff, and administrators but also those responsible for generating curriculum. As our work centers on disability in school, this book is also essential for related service professionals who, by lending their hands, provide much-needed support and services to students to celebrate every goal. Also aimed at faculty who prepare the next generations of classroom teachers to expand their ways of knowing, as well as people who are conducting research on the impact of incorporating diverse and multiple perspectives, this work contextualizes and broadens their understanding of lived experience.

We hope the reader will appreciate the richness, power, reality, and upliftment conveyed through these stories of unbridled love.

Lydia Ocasio-Stoutenburg and Yuchen Yang, Editors

Learning Objectives

In this book, the reader will learn about the following:

1. The multiple, contextual, cultural, and complex perspectives on the experience of disability.
2. The role that practitioners, family members, peers, and all members of the community play in the individual's experiences, as well as that of their caregivers and siblings.
3. The challenges in the systems and support that exist for people with disabilities and the ways in which they need to change.
4. How people who lead with an ethic of love care for, believe in, and advocate for people with disabilities, and how this informs their future practice.

1

A Parent's Fight: Nurturing Identity, Overcoming Adversity

Aimee Granada-Jeronimo

I was only five years old when my kindergarten teacher slapped me across the face. The moment her hand touched my face, I felt the air escape my lungs. I was incredibly confused as I did not understand why my teacher had just hit me. My twin sister sat in front of me, equally confused and hopeless, unsure of what to do. It took all of my energy to try not to cry and show my teacher how much she had hurt me at that moment. I did not know how to react or what to do as I was always taught by my parents to respect my teachers and elders, and so I remained silent. This was one of the first moments I remember remaining silent when I should have spoken up for myself instead, and it certainly was not the last time. It was only until my sister worked

up the courage to tell my parents what had happened that we found out the reason that my teacher slapped me.

My sister was and will forever be my biggest supporter, right alongside my parents. My parents escaped poverty and war and came to America to find a better life for themselves—the iconic “American Dream”. They never expected to find each other—two people of Portuguese heritage—in America and to fall in love and create a family. From the day they had my sister and me, they were committed to making sure that we had the life they could have only ever dreamed of having as children. Newark, New Jersey, was my parents’ home for 13 years. It was a place where they could freely express their culture, language, and love for each other as two women without fear, but they knew it was not the place where they wanted to raise children. They saved up all their money and moved to our forever home in Caldwell, New Jersey, where I was born and raised.

Sadly, when my parents moved to Caldwell, they faced a new type of war—a war of hatred and discrimination. As immigrants, English language learners, and gay women, the intersectionality of their identities caused them to face discrimination on a daily basis in the heteronormative and homogeneous town. The thing that my parents feared most was that my sister and I would also face the effects of hate because of who they are. To try and minimize that amount of discrimination we would face on a daily basis, and because my parents could not afford childcare in Caldwell, my sister and I went to preschool in the Ironbound of Newark, my parents’ safe haven and the one place that my parents felt comfortable being their true authentic selves.

Newark is a city of diversity, a place where the difference in the human population is celebrated rather than feared. It is where my family was welcomed with open arms; it was our home. My preschool welcomed my sister and me without hesitation, two twin girls who were only three years old and spoke no English, as they accepted children from all backgrounds—children whose stories were similar to mine. Our teachers embraced students of all races, ethnicities, and cultures and taught their students to do the same. My teachers never saw my background as a hindrance to my education but instead understood the importance of my diversity and how it would help shape me into the person I am today.

I faced a big culture shock when I started kindergarten in Caldwell, a place where my house was, but not my home. It was confusing to be learning in an environment in which I was forced to speak only English, in a place where students all shared the same background, and where cultural diversity was lacking, as I had never learned in an environment like it before. My parents always greatly valued education, as it was something that they did not have the joy of easily receiving growing up. They understood that we were lucky enough to live in Caldwell, a place in which we could receive a good, free, public education. They never expected that my sister and I would face as many barriers as we did when they made the decision for us to attend school in the town in which we lived.

The slap across my face was the first of the many challenges that I would face in my education and life. As soon as my parents came to know of the situation, they contacted the school

to find out what had happened. The school was “not aware” of the situation but agreed to facilitate a meeting with my parents and the teacher. When questioned about the situation, the teacher admitted to slapping me but deemed it an acceptable reaction because she did not like how slowly I was turning the pages of my math workbook, and she wanted me to find the page faster. My parents were extremely upset over the situation, but they felt like they had no power or voice to make a change, and thus, without facing any repercussions, she continued to be my teacher. However, my parents were assured that nothing like this would happen again.

Little did I know at the time, and little did my teacher know, that I have a learning disability¹ and auditory processing disorder². This affects my auditory understanding and makes verbal directions hard for me to follow. I was not just turning the page of my book slowly; I had not understood which page to turn to as the classroom was noisy, as most kindergarten classes are, and I was trying to figure out what to do by looking at the page my peers were on. This was one of the first times my disabilities impacted me, but it would not be the last, and it took more than three years for me to even be diagnosed with a learning disability.

After many similar instances with other teachers and with my grades being poor, especially in language arts, my parents began to relentlessly push for me to be evaluated for a learning disability. However, my school was reluctant to have me tested. Looking back, I wonder whether the intersectionality of my parents’ identities made it convenient for my school to overlook their concerns because how could two women—two immigrant women