

**Inclusive Education in Rwanda: Autoethnographic Reflections**

by

Catherine Kayumba Batamuriza

A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

in partial fulfillment of the requirements of the degree of

MASTER OF ARTS

Department of Disability Studies

University of Manitoba

Winnipeg

Copyright © 2024 by Catherine Kayumba Batamuriza

**Abstract**

Rwanda has made progress in promoting inclusive education over the past decade. The Government has established a strong legal framework consisting of laws, policies, and commitment to safeguard the rights of persons with disabilities. Yet despite national and global commitments to equitable and quality education for all (Sustainable Development Goal 4), children with disabilities in Rwanda face significant barriers. This thesis uses autoethnography to address the problem by exploring three interconnected questions: (1) How does my understanding of Disability Studies concepts and inclusion align with or differ from local understandings? (2) How has my understanding of inclusion influenced my professional choices and perspective on implementing inclusive education in Rwanda? (3) What approaches and practices have I observed about inclusive education in Rwanda at the national and local levels? To what extent have these practices influenced the learning outcomes of children with disabilities? The study draws from personal reflections of lived experiences, including academic and professional engagements, and analysis of Rwanda's history, education policy frameworks, and community-level interventions to answer the research questions. Disability studies, equity science, postcolonial theory, and intersectionality provide theoretical insights and thematic analysis for data analysis. The results reveal that colonial legacies continue to shape perceptions of disability and inclusion in Rwanda, often perpetuating stigma and segregation. However, pre-colonial values of Ubuntu and solidarity, which align with equity science, provide a culturally relevant foundation for transformative and inclusive education. At the practical level, interventions such as teacher training, community mobilization, and advocacy for systemic changes, including building disability inclusive infrastructure, demonstrate progress in reducing

barriers. Meanwhile, resource inequities and gaps between policy and practice hinder consistent implementation. The study concludes that achieving inclusive education in Rwanda requires a transformative approach integrating cultural values, resource equity, intersectionality, and reflexive praxis to dismantle systemic barriers and foster inclusive communities of belonging where all children, including those with disabilities, participate fully in quality and equitable education. This research bridges global frameworks (SDG 4) and local realities, offering actionable insights for designing, implementing, and monitoring inclusive education programs adaptable to diverse contexts globally.

*Keywords:* Inclusive education, children with disabilities, Rwanda, Sustainable Development Goal 4, autoethnography, reflexive praxis

### **Acknowledgments**

I thank Dr. Diane Driedger for her kind supervision, dedicated time reviewing my work, and engaging me in critical dialogue on dismantling ableism for a disability-friendly world. I am also grateful to Dr. Nancy Hansen for her passionate teaching, especially on the history of disability—your lessons and encouraging words have a special place in my heart. Thank you to Dr. Clea Schmidt for her close reading of my work and for agreeing to be on my committee. Many thanks to Tanis Woodland for all her technical support throughout my disability studies program.

Moreover, I am grateful to my mom and dad for being my biggest cheerleaders and pouring into my education (and the education of countless others). I cannot imagine doing any of this without you. Your relentless drive to serve Rwandans is inspiring. Thanks also to my close friends and AP family, especially Mish and Maren, for praying, keeping me laughing, and making Winnipeg feel like home.

Most importantly, I would like to thank Rwandan children with disabilities, teachers, head teachers, youth with disabilities, and caregivers of children with disabilities—for sharing their stories with me and allowing me to learn with them. I'm forever indebted to them for welcoming me with open arms. Thanks also to the wonderful children and colleagues at LCS, whose essence and joy of being kept me grounded and in touch throughout the writing of this thesis.

I love you all.

**Dedication**

In loving memory of maama dearest– the woman who taught me always to aim high.

**Table of Contents**

**Abstract..... II**

**Acknowledgments ..... IV**

**Dedication ..... V**

**Introduction..... 1**

**Academic and Professional Overview ..... 3**

**Research Methodology..... 8**

        Equity Science ..... 9

        Autoethnography ..... 9

        Thematic Analysis ..... 13

**Thesis Outline..... 14**

**Interlude: “We Must Dare to Invent the Future!” ..... 18**

**Chapter One ..... 21**

**Disability and Inclusion: A Rwandan Context..... 21**

**As Bold as a Lion: Pushing Back ..... 21**

**Theoretical Frameworks..... 23**

        A Feminist Theory of Agency ..... 23

        Interlude: Employment of Disabled Women in Education ..... 26

        Interlude: Living Between Hearing and Deafness..... 28

        Individual Models of Disability and the Persistence of Stigma ..... 31

Social Model of Disability.....	38
Social Theory of Disability as Oppression .....	40
Intersectionality in Disability Studies.....	41
<b>Historical Analysis.....</b>	<b>42</b>
The Evolution of Disability .....	42
Interlude: “Deaf Out Loud” .....	46
<b>Reclaiming Traditional Rwandan Values of Inclusion .....</b>	<b>47</b>
Postcolonial Theory .....	48
Rwandan Culture: “Kubaho nu Kubana”– “to be” is “to be with” .....	49
Segregation of Children with Disabilities in Education .....	51
<b>Chapter Two.....</b>	<b>53</b>
<b>Transforming Perspectives on Inclusive Education .....</b>	<b>53</b>
<b>    The Transformative Potential of Education .....</b>	<b>53</b>
<b>Tensions between Utilitarian and Transformative Frameworks in the SDGs .....</b>	<b>54</b>
Inequality in Education: Where are Children with Disabilities?.....	56
Interlude: My First Inclusion Job in Canada .....	57
<b>The Evolution of Inclusive Education and the Need for Equity .....</b>	<b>60</b>
<b>The Concept of Inclusion.....</b>	<b>60</b>
Interlude: Supporting Children with Autism .....	64
The Problem with “Inclusion” .....	65
Interlude: Navigating the Neutral Zone.....	67

Inclusive Communities of Belonging .....	68
Interlude: “A Seat at the Table” .....	69
Inclusive Education .....	71
Interlude: A Deaf Child in a Rwandan Public Classroom.....	73
Overview of Inclusive Education in Rwanda .....	75
Interlude: Reading “Pedagogy of the Oppressed” .....	77
<b>Chapter Three .....</b>	<b>80</b>
<b>Inclusive Education Practices in Rwanda: Progress and Challenges .....</b>	<b>80</b>
<b>Interlude: Umuhoza’s Right to Education.....</b>	<b>81</b>
<b>Implementation of Inclusive Education in Rwanda: Approaches and Practices .....</b>	<b>83</b>
<b>Part 1: Observations About Inclusive Education at the Local/Village Level .....</b>	<b>84</b>
Interlude: All Children Deserve Accessible Books to Read.....	85
Intersectionality: Most Inequality Starts in Childhood.....	86
Disability Awareness is Key to Eliminating Attitudinal Barriers .....	88
Poverty Causes Disability, and Disability Causes Poverty .....	90
A Twin-Track Approach for Social Protection and Poverty Alleviation .....	92
Education Needs to be a Community Affair: ‘It Takes a Village to Raise a Child’ .....	96
<b>Part 2: Observations About Inclusive Education at the National Level .....</b>	<b>98</b>
Institutional Framework for Inclusion: The SNIE Unit.....	99
Teacher Capacity .....	102
The Principle of “Nothing About Us with Us”.....	107
Dissemination of SNIE Policy.....	109

Service Providers and the Media .....	110
School-Community Partnerships .....	110
<b>Conclusion .....</b>	<b>114</b>
<b>Reimagining Inclusive Education in Rwanda .....</b>	<b>114</b>
<b>Implications for Policy and Practice.....</b>	<b>117</b>
Policy Recommendations .....	117
Practical Steps.....	118
<b>References .....</b>	<b>120</b>
<b>Appendix A .....</b>	<b>1</b>
<b>Journal Entry: Disability and Poverty .....</b>	<b>1</b>
<b>Appendix B .....</b>	<b>3</b>
<b>Journal Entry: Doing Development and Research in the Global South .....</b>	<b>3</b>
<b>Appendix C .....</b>	<b>5</b>
<b>Journal Entry: Media Representation and Mental Health .....</b>	<b>5</b>
<b>Appendix D .....</b>	<b>7</b>
<b>Journal Entry: Building bridges through digital media (“The Kwibuka podcast”).....</b>	<b>7</b>
<b>Appendix E .....</b>	<b>9</b>
<b>Journal Entry: Poetry and Digital Media Bridges .....</b>	<b>9</b>

## Introduction

“Stories are data with a soul.” (Brené Brown, n.d.)

As a high school student in Rwanda, I began to slowly and quite obsessively wonder how and what it would take to achieve an equitable and just society where any girl anywhere in the world could pursue their dreams, free from violence and oppression. I wondered if it was possible to live in a world that is free of hunger and poverty. In Canada, while pursuing further studies (a bachelor's and master's degree), I began to see intersectionality and how particular positionalities marked by inequalities affect some girls and women more than others—because they are ‘multiply’ oppressed (Crenshaw, 1989; hooks, 1984). The more I learned as a political economy major (bachelor's degree), the more I believed a hunger-and-poverty-free world is possible with resource equity.

Resource equity in education “is the allocation and use of resources— people, time, money – to create student experiences that enable all students to reach empowering, rigorous learning outcomes, no matter their race or income” or other marginalized identities, such as disability and sex (Travers, 2018, p.1). Resource equity comprises eleven dimensions that directly and indirectly impact the student experience. Seven factors directly affect the student experience, including 1) teaching quality; 2) empowering, rigorous content; 3) instructional time and attention; 4) early intervention; 5) early learning; 6) whole child approach; and 7) family academic engagement (Ibid, p.1-3). Indirectly, student experiences are affected by school funding, school leadership quality, diverse inclusive schools, and learning ready facilities. As a disability studies graduate student, I saw how people are disabled by social barriers, including resource inequities, and not impairment in the body (Abberley, 1987; Barnes, 1991).

I came across Thomas Sankara, former president of Burkina Faso, early on in my education journey, and he remains a big inspiration (and one of my biggest cheerleaders, if I may say so myself). Sankara so inspired me that I made it my mission as a grade 12 student to study his policies and make knowledge pieces about his approach to freeing the people of Burkina Faso from poverty and dependence on Western colonizers. I wrote an extended essay about him in my International Baccalaureate higher-level history course and created an art mural on him. In one interview with Swiss Journalist Jean-Philippe Rapp in 1985, Sankara stated:

You cannot carry out fundamental change without a certain amount of madness. In this case, it comes from nonconformity, the courage to turn your back on the old formulas, and the courage to invent the future. It took the madmen of yesterday for us to be able to act with extreme clarity today. I want to be one of those madmen. . . We must dare to invent the future. (Interview with Jean-Philippe, 1985)

These words struck a chord when I first read them and still inspire me today— especially in moments of frustration. Changes in my worldview and personal and professional transitions marked my twenties. Change and transition are scary— often, I was scared of getting it wrong. This is because change and transition imply leaving home, letting go of what is familiar, and inhabiting the wilderness as we travel from one identity to another. I use the word wilderness (or the scary unknown) intentionally, and it is a word I have come back to repeatedly. Looking back on my journey from a curious and unsettled undergraduate student to a full-time development professional and graduate student intent on writing my story, I see the stressful impact of navigating the journey from one identity (worldview) to another. My journey through the

wilderness from one point to another can be defined by three stages, including (1) endings, (2) the neutral zone, and (3) new beginnings (Bridges, 1991).

In the book, “Managing Transitions: Making the Most of Change,” Bridges (1991) argues that change and transition are not the same thing, as they tend to be confused. When I talk of change, I refer to environmental and situational things, while transition marks “the ending that [one] has to make to leave the old situation behind. Situational change hinges on the new thing, but the transition is psychological and depends on letting go of the old reality and your old identity before the change occurs (Bridges, 1991, p. 1). The hardest time for me during change and transition in my twenties was in “the neutral zone” (wilderness), a time of transition between the old and the new. Adjusting to change takes time and is neither linear nor a perfect progression. It has been messy and beautiful at the same time. It was a time of big ups and downs. But I would not have been so hard on myself if I knew what I know now. The departure from home (an old, disempowered self) opened the beautiful door to empowerment (or confidence), growth, experimentation, and innovation. It also brought along grief, failure, immobilizing fear, and self-doubt. I ruffled many feathers along the way and made mistakes as a leader doing “equity work” in international development work to serve children, my favorite humans on earth.

### **Academic and Professional Overview**

My understanding of who I am began to shift drastically as I grappled with and inhabited a world where most people I met, especially white people, who had heard anything about the 1994 Genocide against the Tutsi in Rwanda made it a point to tell me sheepishly “Oh, I watched “Hotel Rwanda,” or “Is it safe now?” A few black African people from the Great Lakes region

would say, “Oh, Kagame!” and they would proceed to add something like, “He is a dictator!” or “I like Kagame. Our president needs to take a page out of Kagame’s book!” These comments, even though usually said innocently, felt very loaded and sometimes even triggering.

Understanding Africa’s history, decolonization, and women's empowerment became critical as I worked to complete my first degree. My positionalities shifted in professional practice (childcare in Canada and education in Rwanda) and graduate school (Disability Studies program at the University of Manitoba) from the traditional models of disability (medical and charity models) to the social model of disability as oppression (Abberly, 1987; Cleall, 2015; Driedger, 2021; Oliver, 2013; Shakespeare & Watson, 2010; UN 2006). This change and transition impacted my understanding of disability inclusion and influenced my professional choices and perspectives on the design and implementation of inclusive education in Rwanda.

I do not come from an academic education training background, but much of my professional career thus far has been in the education and childcare sector. I grew up as a firstborn and embraced a caregiving role to my siblings in various complex family dynamics at a young age. Furthermore, at eighteen, I got my first job as a summer school teacher and preschool teaching assistant at Green Hills Academy, my former primary and secondary school. That first year of formal employment was exhausting yet so fulfilling. Most Rwandan schools then had a full seven or nine-hour day, typically from 7:30 am or 8:00 am to 3:30 or 5:30 pm. But since 2022, public primary schools have shorter days with double shifts, including morning or afternoon, and students attend one. Early on, I fell in love with working with preschoolers (my favorite age group) and children in the early years of school (kindergarten to grade three). They inspire me to be the best researcher and human being. Their energy is contagious, and their constant “why-s,” “what/how about this and that,” “did-you-knoow?” and over-the-top “guess

whaaaaat?” got me up in the morning excited to see what new stories, inquiries, and pushbacks the new day would bring.

When I went to college, I ventured into different roles in the retail and entertainment sector for three years before returning to childcare and development. But even during the time that I was not working directly with or for children, I stayed connected in some way as my long-term motto remains: “Work for world peace, heal your inner child,” a slogan I got from John Bradshaw’s 1992 book “Homecoming: Reclaiming and Healing Your Inner Child.” I also did a lot of my university research work on child-related topics. As an undergraduate student, I did a year-long research project on the mental health of refugee children in Canada. Through my early undergraduate days, I learned that the principles of justice, equity, and human rights were important to me. I made many lifestyle choices and decisions to align with this, including starting a black women's reading club to foster community and sisterhood or what bell hooks calls “Sisters of the Yam” (hooks, 1993). I diversified the voices that speak into my life through art, academia, and social media after I learned from the “Women and Gender Studies” course how women’s work is undermined in all sectors of society. I consciously decided to center post-colonial, black, and third-world women in my work and personal choices. My life and research were and continue to be influenced by feminist scholars and writers, including bell hooks, Audre Lorde, Maya Angelou, Toni Morrison, Alice Walker, and Chimamanda Ngozi Adichie.

In 2017, I got my first job in inclusion as an Inclusion Support Worker at a school-based childcare center. Upon completing my first degree at the University of Manitoba in Canada, I returned to Rwanda to pursue a career in international development. In Rwanda, in the international development sector, I started thinking seriously about inclusion and its meaning. Within three weeks of leaving my childcare job in Canada, I started my first development work

in 2019 with a large international development agency. I realize today that this transition from a Western university to doing development work in some of the most impoverished communities and with marginalized groups, including youth and children with disabilities, made me deeply aware of inequity, including my privilege and power, in a new way. I grew up in a middle-class household and attended a private primary and secondary school in Rwanda's capital, Kigali. My classrooms in the private school I attended were small, with approximately twenty-two to thirty students per room, and well-equipped with competent teachers, the right educational materials (textbooks and other scholastic materials), good ventilation, lighting, and appropriate furniture (per student needs). In secondary education, we followed the Cambridge and International Baccalaureate education curriculum instead of the national curriculum.

Most of the classrooms I visited during my fieldwork across the country were overcrowded, with over fifty students per room. They lacked adequate resources, including people, time, and money, to create student experiences that enable all children to reach their full potential (World Bank, 2023; Mutezigaju, 2019; Save the Children, 2021; Karangwa, 2013; 2006). Teachers often complained that they were not well-equipped with appropriate training, tools, and resources to teach to the best of their ability, let alone provide individualized education to children with disabilities. In the rural villages of Rwanda, as I interacted with poor single mothers, disabled children, and teachers in public schools while promoting literacy and inclusive education on different projects funded by different international development agencies and multilateral organizations, I found myself questioning and re-examining my role in the machinery of oppression (reflecting on my own pre-existing beliefs and biases).

In my various roles in Rwanda from 2019 to 2023, I worked directly with people with disabilities and organizations founded and run by them. While I am proud of our work (I will go

into this in more detail in chapter three), the mission to meaningfully accommodate children with disabilities in our current education system eluded me. I enrolled in a Master of Arts in Disability Studies to understand how to reach this goal and give quality basic education to children with disabilities in the most impoverished villages in Rwanda. I worked with multilateral organizations and leading international development firms on different projects, both at the District or local level (working directly with community volunteers and village leaders to promote inclusion) and national level (working directly with national leaders in education at the Ministry of Education, Rwanda Basic Education Board, National Examination and School Inspection Authority, and the University of Rwanda). On one project, I worked with an organization of persons with disabilities to design and implement a year-long pilot of disability inclusive approaches to community-based literacy promotion in five districts, reaching over three thousand five hundred families of children with disabilities, one hundred thirty-seven youth volunteers with disabilities and seven hundred sixteen Community Education Workers (Save the Children, 2021; 2022).

On another project, national in scope, I worked with different organizations of persons with disabilities, particularly the Rwanda Union of the Blind, and implementing agencies of the Ministry of Education (MINEDUC), including Rwanda Basic Education Board (REB), the National Examination and School Inspection Authority, and the University of Rwanda to improve capacity and promote disability inclusive policies and practice in schools and teacher training colleges. In this thesis, I explore my evolving understanding of disability and inclusive education (in the neutral zone) and how it has influenced some of my professional choices and decisions regarding its design and implementation in Rwanda. I will do this by examining major disability and inclusion approaches, choices, and decisions taken at the local and national levels

of education (both formal and informal or community-based). The goal is to share the lessons learned through the changes and transitions in my personal and professional journey in inclusive education by looking at what worked well, what did not, and why. This can help to guide and inform development work, government, and others interested in promoting the full participation of persons with disabilities in their communities—particularly in basic education.

### **Research Methodology**

As someone whose entire academic journey in Rwanda and Canada was founded on an Amer-Eurocentric and white supremacist worldview, an examination of my personal and lived experiences is crucial to center my values of equity science and Indigenous ways of living in the world. Indigenous ways of living are defined by Rwandan cultural values (as specified and explained in Chapter One). This thesis aims to help others and me understand and make the most of change and manage transitions well, particularly regarding inclusive education. It is critically important to me that whatever I do, including my research paradigm, serves the needs of and benefits the local community. Plamondon and Shahram define a paradigm as “a system of beliefs that include ontological, epistemological, axiological, and methodological assumptions underpinning scientific inquiry” (2024, p. 5). Or, in simpler words, as defined by Cree scholar Shawn Wilson (2001), it is “a set of beliefs about the world and about gaining knowledge that goes together to guide people’s actions as to how they are going to go about doing their research” (p. 175). Wilson’s definition, like Plamondon and Shahram's (2024) above, includes four aspects:

Ontology or a belief in the nature of reality. Your way of being, what you believe is real in the world...Second is epistemology, which is how you think about reality. Next, when we talk about research methodology, we are talking about how you are going to use your

way of thinking (your epistemology) to gain more knowledge about your reality. Finally, a paradigm includes axiology, which is a set of morals or a set of ethics. (p. 175)

My scholarship must not negatively affect or harm the community or compromise my integrity. Therefore, I embrace equity science as it most aligns with Indigenous ways of living in the world, including Rwandan and Ubuntu philosophies.

### **Equity Science**

Equity science is “the scientific study of processes, methods, and practices required to advance equity through systems-level action on its determinants” (Plamondon and Shahram, 2024, p. 5). Equity is (a) a conceptual construct, (b) a benchmark (“something it aims to achieve), and (c) an experience that interrogates and redistributes power and resources fairly through participatory, trans-disciplinary, action-oriented, and emancipatory methodologies (Ibid, p. 3). The equity worldview states, “Humanity is relationally bound to one another and to the Earth” (Ibid). This worldview aligns with the Rwandan worldview, where “to be” is “to be with” (“Kubaho nu Kubana”) and the African philosophy of Ubuntu, where “a person is a person because of or through others” (“Umuntu Ngumuntu Ngabantu”) (Moloketi, 2009, p. 243; Tutu, 2004, p. 25-26; Translation from Nothomb, 1965, p. 148, cited in Karangwa, 2006, p. 21). I must add that in Kinyarwanda, the word “ubuntu” literally means generosity. When someone is generous, we say, they have “ubuntu.” I elaborate further on Rwandan and Ubuntu philosophies in Chapter One.

### **Autoethnography**

I use autoethnography as a qualitative research method to explore how equitable and inclusive education can be implemented in schools to create student experiences that enable all children, including children with disabilities, to reach empowering, rigorous learning outcomes,

regardless of ability, gender, ethnicity, geographical location, family background, family income, or other characteristics. Inclusive and equitable education involves eliminating barriers that hinder learners' participation and academic achievement and recognizing that each student possesses unique needs, abilities, and characteristics that warrant respect and accommodation (UNESCO, 2009). Autoethnography also involves allocating and using resources, including people, time, and money, equitably based on need. Ellis and colleagues define autoethnography as “an approach to research and writing that seeks to describe and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno)” (2011, p. 274). Autoethnography examines how the researcher’s past experiences, viewpoints, and roles influence their interactions with and interpretations of the research scene through active self-reflexivity (Tracy, 2020, p. 2).

Autoethnography involves the use of personal experience to tell a story that “evokes readers to feel and think about [their] life and lives in relation to [the researcher] . . . to experience the experience [written] about” (Ellis, 1999, p. 674). It is a powerful qualitative research method because it utilizes a researcher’s world and intimate details of their life to produce analytical and accessible texts to change the reader and make the world more socially just and fair (Ellis et al., 2011, p. 274). Similar to methodologies of equity science (previously described), autoethnography involves using primary data through observational, participatory, and reflexive data collection techniques of narrative research (Poulos, 2021). This research is based on my academic and professional experiences in Rwanda and Canada. I used reflective journaling, real and imaginary conversations, interactions, storytelling, field notes, and research findings to answer the research question. Generalizability is achieved by speaking to readers in a

way they can identify with and illuminate general but unfamiliar cultural processes to them (Ellis et al., 2011).

Throughout my professional journey, I have been documenting my observations and experiences on the field, especially the things that surprise, excite, and anger me. A lot of these observations have been shared in internal and external published reports (for example, Save the Children, 2020; 2021; World Bank, 2023). Also, starting in February 2022, I started jotting down brief notes on all areas of my life, and I used these to produce a more detailed and chronological dataset. This helped me to process and critically analyze myself in contact with others to “illuminate the many layers of human social, emotional, theoretical, political, and cultural praxis (i.e., action, performance, accomplishment)” (Poulos, 2021, p. 6). My journals (see a few examples in Appendices A - E) helped me bring together all aspects of my study and life. These journals explore different themes and were done as part of the coursework for disability studies.

As such, I primarily rely on self-reflection for a comprehensive data set. Self-reflection through journaling is considered a method of discovering and framing truth. According to James and Bushner (2006, p. 62), reflective journaling is associated with “allowing them [researchers] to move back and forth through their narratives, thinking about their responses, drafting and redrafting what they want to write. This process forms a more grounded approach that improves understanding of academic experiences and allows the researcher to “mull over ideas, uncover inner secrets, and piece together life’s unconnected threads” (Ibid). Furthermore, autoethnography requires “both personal and scholarly” aspects, so the writing “is both descriptive and theoretical” (Burnier, 2006, p. 414). So, I showcase personal narratives through a theoretical framework to make contributions to knowledge.

A lot of my personal reflections and professional reports were informed by tools I picked up from graduate school (for example, History of Disability, Women and Disability, Disability and the Media, Global Disability Studies) and undergraduate courses (Women and Gender Studies, Cultural Anthropology, Sociology, History of Africa, Global Political Economy). More specifically, I learned early on in my Women and Gender Studies course and anthropology that “the personal is political.” A key lesson I learned from one of my favorite teachers and feminists, Audre Lorde, is (and I reiterate elsewhere in this thesis) that “... what is most important to me must be spoken, made verbal and shared, even at the risk of having it bruised or misunderstood. That the speaking profits me beyond any other effect” (Lorde, 2016, 1:24:40).

So, I chose to highlight memories based on what is most important to me and my values of equity, inclusion, and true belonging. I have imaginary conversations with academic scholars and leaders who inspire me. These imaginary conversations came to me as I re-read, listened to, and continually reflected on specific works that resonated deeply with my data and its associated emotions. Specifically, the imaginary conversation with Audre Lorde (2016), Thomas Sankara (1985), and Brené Brown (2010, 2017) came as I grappled with feelings of discomfort, fear, and doubt during data analysis and synthesis. Their works have encouraged me separately throughout my journey, and I brought them together in conversation as they validated the difficult feelings that come with a close cross-examination of one’s lived experiences. Their words often gave me fuel to lean into the discomfort of the neutral zone, before my data began to tell a coherent story (Bridges, 1991). As mentioned earlier in the introduction, the neutral zone is a time of transition between the old and the new and can be a confusing time (Ibid). In my case, one of these transitions came during my data analysis as I was looking at and familiarizing myself with old

stories or lived experiences through theoretical lenses to uncover their social meaning (further explored in “Interlude: Navigating the Neutral Zone” in Chapter Two).

### **Thematic Analysis**

I used Braun and Clarke’s (2006, 2012, 2020) thematic analysis procedures to analyze my data. Data analysis involves familiarizing and organizing data using preliminary codes to describe and make sense of the content through the social model of disability and equity science from an Indigenous and feminist lens. Following the creation of preliminary codes, themes were generated, reviewed, defined, and named across the data with intersectionality in mind. This analytical process allowed me to understand the meaning of my experiences as an equity and inclusion professional (Ibid). Specifically, I focused on the thematic organization of my personal and professional experiences implementing inclusive education practices with various stakeholders, including children with disabilities, caregivers of children with disabilities, youth and adults with disabilities, international organizations, local organizations of persons with disabilities, and governmental and non-governmental organizations.

Lastly, autoethnography carries a heavy ethical burden. I use protective devices such as altering identifying characteristics such as name, gender, race, place, or appearance to protect the privacy of all individuals in the study. All the names of the people mentioned in this thesis have been changed. I also only share details about my professional work if they are public information— as in, they have been approved to be shared publicly through presentations, reports, papers, articles, and other documents. Protective devices provide meaningful and reliable narratives that accurately reflect actual events without compromising the confidentiality of participants (Ellis, 1999).

### **Research Questions**

My first research question explores the alignment or divergence between Disability Studies concepts and local understandings of inclusion in Rwanda. Secondly, I examine how my understanding of inclusion influenced my professional choices and perspectives on implementing inclusive education in Rwanda. Lastly, I assess existing practices and approaches to inclusive education and their impact on learning outcomes for children with disabilities. By critically reviewing my education and professional experiences, this study aims to identify successes and opportunities for improvement to foster positive change within the education sector in Rwanda. Therefore, the study addresses the following research questions:

1. How does my understanding of Disability Studies concepts and inclusion align with or differ from local Rwandan understandings?
2. How has my understanding of inclusion influenced my professional choices and perspective on implementing inclusive education in Rwanda?
3. What approaches and practices have I observed about inclusive education in Rwanda at the national and local levels? To what extent have these practices influenced the learning outcomes of children with disabilities?

### **Thesis Outline**

In the first chapter, I examine how my understanding of disability studies concepts aligns and differs from local understandings in Rwanda. I trace how my understanding of disability has changed throughout my career and graduate studies from a more medical and charity orientation to my current approach, which is underpinned by the social theory of disability as oppression. I employ the concept of oppression for a social theory of disability as oppression. Colin Barnes argues that the term “disability” represents a complex system of social restrictions imposed on people with impairments by a highly discriminatory society— where “to be disabled means to be

discriminated against” (Barnes, 1991, as cited in Abberley, 1991, p.2). As such, the theory of disability as oppression:

connects together the common features of economic, social, and psychological disadvantages with an understanding of the material basis of these disadvantages and the ideologies which propagate and reproduce them. It is specific and systematic– so it moves discussion beyond the level that it has reached so far, by bringing to bear the tools of today’s social science, rather than those of the day before yesterday. (Abberley, 1991, p. 17)

Oppression reflects hierarchical power relations derived from sex, class, race, (dis) ability and is “manifested through both the material and ideological dimensions of patriarchy, racism, capitalism” (Eisenstein, 1979, p. 22-23, as cited in Abberley, 1991, p. 8). Accordingly, disability is marked by five critical features of oppression (Abberley, 1991). First, it is specific in form, content, and location. “This means pointing to the difference between disabled lives and those of other sections of life, including those who are, in other ways, oppressed” (Ibid, p.17). Second, members are in an inferior position to other members of society simply by belonging to the group. Third, the marginalization and disadvantages disabled people face “are dialectically related to an ideology or group of ideologies which justify and perpetuate this situation” (Ibid, p. 17). Fourth, disadvantages and their supporting ideologies are neither natural nor inevitable. Fifth, it involves the identification of some beneficiaries of inequitable and unfair state of affairs (Ibid, p. 17). This can be seen in the evolution of disability through history, for example, what it means to be Deaf.

Similarly, the American philosopher and feminist theorist Marilyn Frye uses the cage metaphor to explain the systematic nature of oppression and how various barriers and forces interact and shape the lives of oppressed people.

The experience of oppressed people is that the living of one's life is confined and shaped by forces and barriers which are not accidental or occasional and hence avoidable but are systematically related to each other in such a way as to catch one between and among them and restrict or penalize motion in any direction. It is the experience of being caged in... all avenues, in every direction, are blocked or bobby trapped. (Frye 1983, p. 4)

I propose this notion of oppression as a system of various barriers and forces that intersect and interact to shape the lives of disabled people. This understanding is the basis for my thesis and is a useful tool for transforming education for disabled children in Rwanda. My early experiences (for example, partial deafness or hearing) and knowledge of disability came from directly working with children with disability, particularly children with autism. This taught me to see the humanity of people with impairment, which is lost through the medical and charity models of disability (the traditional view of deafness as a disease to cure, hide, and pity). Evidence from work led by organizations of persons with disabilities and development interventions for disability inclusion in Rwanda shows we, as human subjects, have the power and agency to create enabling conditions to transform our society, free from oppression and injustice.

Agency means self-definition and self-direction. It is variable, context-specific, and non-unitary. It is the ability one has to direct one's life course. Multiple social influences and variables intersect at any given time and place and affect a person's ability for self-direction. This intersection bears on us to form our trajectory of self-assertion (Abrams, 1999, p. 845).

Kathryn Abrams suggests two dimensions of agency: self-definition and self-direction—including “agency as resistance, the range of institutional and social targets concerning which agency may be exercised, and collective aspects of its genesis or exercise of agency” (Ibid, p.824). According to Paulo Freire's argument, true liberation requires the oppressed to participate actively in their education and transformation. Through education (critical consciousness), employment in development for disability inclusion (dialogue, practice, reflexive praxis), and engagement with people with disabilities (knowledge through practice), I gained the tools for self-definition and self-direction. It was the same process and outcome (self-definition and direction) for the people I worked with, particularly colleagues with disabilities, including teachers with disabilities (as detailed in chapter three).

In chapter two, I explore how my understanding of disability inclusion influenced my professional choices and perspective on implementing inclusive education in Rwandan schools for liberation and belonging. Acquiring quality liberatory education is essential for achieving equity and empowering marginalized individuals. I reflect on the meaning of inclusion, how oppression works, and the historical evolution of disability to uncover the hidden devices used to demonize, displace, dehumanize, and disempower people with disabilities. Or, as one of my professors put it during a coffee meet-up, disabled people come to tell us, “We are human too!” Disability is a human rights issue. People with impairment (visible or otherwise) have a right to get quality education and to belong (among other human rights), without discrimination, in their communities fully. Disability aligns perfectly with the Ubuntu philosophy of “I am because we are,” upon which traditional Rwandan values can be traced back to before colonization and the formalization of education and segregated schools. I show how the advent of special education

for children with disabilities in Rwanda during colonialism marked the beginning of segregation and current discrimination against persons with disabilities in Rwanda. Before colonialism, persons with disabilities belonged and were accepted in their communities.

Finally, in chapter three, I examine approaches and practices used to implement inclusive education at the national and local levels in Rwanda and the impact of these practices on my learning of children with disabilities. I share memorable stories and observations from my field travels across Rwanda to shed light on some of the complexities, realities, and impact of implementing an inclusive education policy and practices in Rwanda at the national and local levels. My visits were for various activities, including monitoring the implementation of different inclusive school-based or community-based education project activities, assessments, and research initiatives. My observations demonstrate some progress in addressing barriers faced by children with disabilities and their families. However, the effectiveness in improving learning outcomes depends on sustained resource equity, including teacher training, building accessible infrastructure, strong community engagement and partnerships between different stakeholders, research and evidence-based advocacy to ensure equitable and transformative inclusive education.

### **Interlude: “We Must Dare to Invent the Future!”**

After a very rough period of becoming undone by all the lies I believed about who I was throughout girlhood, I felt frustrated. I falsely believed that I was not making nearly enough progress toward becoming the woman of my dreams, and I felt fear and self-doubt. I was reminded of the words of three people who inspire me: Thomas Sankara (Interview with Jean Philippe Rapp, 1985), Audre Lorde (2016), and Brené Brown (2010, 2017). They all address the

need to lean into the discomfort to create the social change we want to see. I imagined them giving me a pep-talk (the conversation is made up and is inspired by key themes in their work):

Sankara (Interview with Jean Philippe Rapp, 1985) says firmly but kindly: “Perhaps you feel stuck and do not yet have the answers because you are using old formulas.”

Lorde (2016) nods gently in response and adds: “Yes, sunshine, feelings are good. You feel, therefore, you can be free. The erotic is an important source of power and information within your life. As soon as women begin to feel all aspects of their lives deeply, (1) they demand personal and societal transformations that align with the joy they know they can experience. The erotic empowers one to advocate for change within themselves and society. (2) Sharing this pursuit with others in the community will grant you the power to make you feel emboldened, fearless, and authentic as you pursue joy and truth. (3) Always remember the tools of the oppressor will not liberate you. You must invent new tools that align with your values and desire to be free. The research you’re doing is a great start.

Brené Brown (2010, 2017) acknowledges Lorde and says with a knowing smile: “I know that feeling—the uncertainty of whether your hard work, labor, and authenticity will bear the fruits you desire. Lean in; don’t give in to the temptation to numb. You can watch an entire series for a day or two, but do not allow yourself to stay there long. I went to therapy for over a year when my research findings shook me to the core. I came out of that season a little braver than before. We cannot selectively numb emotions. When we numb painful emotions, we also numb positive ones.”

Sankara nods and responds encouragingly: “Courage! Turn your back on the old formulas. It’s your time to invent the future.”

Collectively, I hear, “*We must dare to invent the future. Courage! Courage!*” as their voices and faces fade into the background, and I face the task at hand head-on (at least for a little while).

\*\*\*\*\*

## Chapter One

### Disability and Inclusion: A Rwandan Context

“This is about making sure you know you are important to us, and your education is our priority. Our values and culture must remain the foundation of our children’s education. Let’s continue to base our nation’s transformation on who we are and on instilling a sense of self-worth in our children.” –H.E Paul Kagame, 2016

This chapter examines how my understanding of Disability Studies concepts aligns with and differs from local understandings in Rwanda. I trace how my understanding of disability has changed throughout my career and graduate studies from the traditional medical and charity model to the social theory of disability as oppression. My understanding of Disability Studies concepts, particularly the social model of disability and the framework of equity science, aligns with Rwanda’s historical values of humanism and solidarity but differs from current local attitudes shaped by colonial legacies, which introduced segregation and fostered systemic and attitudinal barriers that continue to marginalize persons with disabilities.

#### **As Bold as a Lion: Pushing Back**

Eighty percent of an estimated one billion people with disabilities live in developing countries and are poor (World Bank, 2022). This fact is not surprising given the ongoing domination and disabling of people in the global south through wars and conflicts “kept alive mostly by super-power politics and by weapons forged and manufactured at the bargain prices in the rich countries, who export death and destruction, and import the natural and partly processed products of the poor countries” (Nobel, 1988, p. 29 as cited in Malkki, 1995, p. 504). As a Rwandan woman, I cannot ignore nor deny the genocide’s impact on my self-concept and the Rwandan community at large. I cannot talk about disability without thinking about the countless

ways the genocide wound us as a people, both psychologically and physically. How does a nation heal and recover from such horror and tragedy? This question remains at the back of my mind like a permanent tattoo that always begs to be seen, especially every April through June during the hundred days of mourning. During the yearly commemoration of over a million loved ones lost in a hundred days, we hold vigils and multiple other events to “Remember, Renew, and Unite” (the national theme). The air is so heavy with sorrow, loss, and betrayal.

April is always such a heart-wrenching time. This year, in April 2024, I saw many mourning Rwandans attack other Rwandans who posted pictures of themselves out and about celebrating and enjoying life during the national commemoration week, which begins on April 7th. The horrors of death and torture, rape, and mutilations are so great that many of us cannot imagine how the world does not stop in the way that W H Auden captures in his poem, “Funeral Blues” (1938):

Stop all the clocks, cut off the telephone,  
Prevent the dog from barking with a juicy bone,  
Silence the pianos and with muffled drum  
Bring out the coffin, let the mourners come.

When I first read Warsan Shire’s poem, “What They Did Yesterday Afternoon,” as an undergraduate student at the University of Manitoba, it resonated so deeply because it acknowledges the reality of our grief, trauma, and ongoing horrors around the world (one need only to turn on the news on any given day):

later that night  
i held an atlas in my lap  
ran my fingers across the whole world  
and whispered  
where does it hurt?

i answered  
everywhere  
everywhere  
everywhere.

We can never forget what happened. Our scars will not let us forget what happened to us. The ongoing horrors around the world will not let us forget. Yet, we stand as bold as a lion as we work hand in hand to heal and transform our nation. You may ask: How do you heal and continue to sustain life when you have a heavy pain-body like ours? The complicated and simple answers lie in our individual and collective agency.

Rwanda is a small, densely populated, low-income, and landlocked country with 13.4 million people (RPHC, 2022). It is located in central eastern Sub-Saharan Africa and has a surface area of 26,338km (km squared). Most of the population resides in rural areas and subsists on small-scale farming. Significant structural inequalities characterize Rwanda, with most of the population living on low incomes. It was through my career in development, starting in 2019, that I began to see and understand the reality of the majority of Rwandans, where fifty-two percent of the population lives below the income poverty line, nineteen point seven in severe dimensional poverty, and twenty-two point seven percent are vulnerable to multidimensional poverty (UNDP, 2023). The gross domestic product (GDP) is 797.9 per capita, and the public debt is estimated at 63.3 percent of GDP (IMF, 2023). Public debt has more than tripled in ten years and was further exacerbated by the COVID-19 pandemic, rising from 19.4 percent of GDP in 2023 to 63.3 percent in 2020 of GDP, while the headcount poverty rate is estimated to have increased to 5.1 percentage points (more than 550,000 people) in 2021.

## **Theoretical Frameworks**

### **A Feminist Theory of Agency**

According to feminist accounts, agency means (a) self-definition and (b) self-direction. Self-definition is “determining how one conceives of oneself in terms of goals one wants to achieve and the kind of person, with particular values and attributes, one considers oneself to be” (Abrams, 1999, p. 824). Self-definition happens when one becomes aware of how they and their self-conception are socially constituted through socialization. This awareness of how one's visions of self are formed through norms embedded in social institutions and practices. It is followed by insights from reflections on experiences or attitudes about comparison with their feelings or intuitions about oneself. In other words, the awareness that comes from self-reflection gives us the ability to consciously choose (a) what images to affirm or strive for and (b) which to reject, resist, interpret, or replace.

The second aspect of agency is self-direction, which is political in nature. Self-direction is the ability to shape and pursue one's goals without “distraction, dissuasion, or weakness of will” (Abrams, 1999, p. 829). We can become free only when we understand how social formation shapes our self-conception and goals. Here again, as we become aware of political barriers, we can choose which goals and conceptions to reject, modify, or affirm. Self-direction involves resistance and transformation (Abrams, 1999). Resistant self-direction is resistance to political barriers to make way for one to direct one's life course in pursuit of one's own goals, plans, and choices. This resistance and self-assertion can be more prominent in some contexts of one's life and not others (for example, at work but not at home or vice versa). Transformative self-direction has to do with explicit resistance to group-based oppression in pursuit of social transformation as one or groups of individuals become aware of broader injustice and inequality (Ibid). For example, the women's equality movement, disability justice movement, the struggle for independence by African countries post World War Two, the Black power movement. This

kind of resistance extends beyond the self or group of individuals towards formal political or legal institutions (Ibid).

Transformative self-direction requires collaboration with others and seeks to transform political inequalities through cultural representations, governmental institutions, social interactions, or the use of language (Abrams, 1999). Due to systematic, institutionalized inequality, Abrams argues that collective action is often necessary to resist or transform entrenched barriers to particular choices or life. This is hard to do alone or in isolation, let alone conceive alternative goals or plans because of the internalization of these barriers through socialization. We need to work with others to loosen dominant forms of socialization (Ibid). Accordingly, resistance aimed at political or legal institutions encompasses and addresses cultural representations, social interactions, use of language, and government institutions that produce and reproduce inequality (Ibid).

Many feminist constructivists describe what Kirstie McClure has called the “diffusion of the political”: that the power to produce political inequalities emanates not only from the institutions of the political system per se, but from social, cultural, and linguistic practices. Resistance that seeks to transform these inequalities, therefore, may be directed not simply at governmental institutions, but at social interactions, cultural representations, or use of language as well. (Abrams, 1999, p. 832)

When an individual female subject understands how social formation shapes their self-conceptions and goals, they can choose to affirm, reject, or modify them. They can do this as obstacles imposed upon one because they are a woman become apparent. For example, being aware of how a patriarchal system marginalizes women through negative social norms, exposes constraints to women’s choices, deprecation of their abilities, or “practices that intimidate,

belittle, or degrade” them (Abrams, 1999, p. 830). These forms of interference may prevent a woman from exploring or achieving various goals. Awareness of the political obstacles gives way to women’s resistance (subtle and overt) and opposition. This is certainly how persons with disabilities, particularly women and their organizations, are making waves in Rwanda and playing a pivotal role in improving living conditions for children, youth, and adults with disabilities.

From blind teachers and professors mobilizing and demanding equal access to quality education and employment of persons with disabilities (World Bank, 2023). To youth with disabilities leading awareness campaigns in their villages to eradicate stigma and share practical knowledge around the inclusion of children with disabilities in education and literacy at home (Save the Children, 2021; 2022). Communities all across Rwanda are witnessing people with disabilities taking charge alongside other Rwandan women and men to shift behavior and change how disabilities are perceived.

### **Interlude: Employment of Disabled Women in Education**

I met a blind teacher, Mukiza, during a teacher training on inclusive education. She spoke confidently about ableism and how it hinders the full participation of persons with disabilities in Rwanda’s development. She told me she aspired to be a teacher since she was a little girl– and never stopped reaching for this, even when the barriers seemed insurmountable. She thought she had finally arrived when she passed her teaching examination with high points, only to get to her job at a school in Kigali, and was denied a classroom to teach for months because of negative perception about disability and lack of reasonable accommodation at the school for teaching. The head teacher offered her to visit different classes every day to learn how to teach while they

worked on ways to accommodate her. Mukiza held on to her dream and did not let this setback, although discouraging, stop her.

Mukiza's story reflects Abberley's argument that systemic economic exclusion is a form of oppression. People with disabilities are denied access to equal opportunities and dignity worldwide. Studies show that disability significantly predicts unemployment (Banks & Polack, 2017; International Labour Organization, 2024). People with disability also earn less (26 percent less per hour than non-disabled people in low and lower-middle-income countries) and tend to be self-employed (International Labour Organization, 2024). These numbers are lower for women with disabilities as they also face a substantial gender pay gap— by 6 percent in countries where gender disaggregated data is available (Ibid). Furthermore, disability onset for women is associated with gender inequality (Lee et al., 2021; Mora, Schwarts Orellana, & Freire, 2021).

Resource equity, such as investing in teacher training in inclusive education and disability rights campaigns, is crucial for ending systemic oppression. Following our training and hearing from experienced teachers with disabilities from across the country, Mukiza's school management learned and identified ways to reasonably accommodate her and students with disabilities. Interestingly, the cost was not as high as they initially assumed. The Director of Studies also started raising the awareness of other teachers at the school to make them more accepting of disability and to treat her as an equal. The Rwanda Basic Education Board also gave her a laptop with accessible software.

Furthermore, dismantling systems of oppression cannot happen without removing power imbalances, summed up in the powerful adage of the disability movement: "Nothing about us without us." In education research, studies show that men and women with disabilities often get into the teaching profession because of their personal experience as students with disabilities

(Duquette, 2000; Ferri, Keefe, & Gregg, 2001). The life stories and experiences of teachers with disabilities throughout education influence their drive and how they teach. In a study by Dvir (2015), three student teachers with physical disabilities (one with a mobility impairment, another who is deaf, and one with scoliosis) were asked to write their professional life stories, paying particular attention to their choice of teaching as a profession. The qualitative narrative analysis revealed that their professional identities were affected by their life narratives, more specifically, the exclusion and discrimination they experienced as a result of their disability. The schooling experiences of all three participants were marked by exclusion and the painful feeling of not belonging. These findings also mirror the life narratives of teachers with visual impairment in Rwanda, whose stories reveal the insidious ways the traditional model of disability disadvantages and marginalizes persons with disabilities in education.

Mukiza remains optimistic and determined to be the best teacher she can be, even though she still encounters physical and communication barriers. For example, she only has one textbook in soft copy for her English lessons, and she spends her own money to buy teaching tools. More than anything, her goal is to independently teach her students without always relying on a teaching assistant for everything. In her particular case, independent teaching is possible with teaching resources in Braille, a projector, and electricity in all her classes— showing that disability is caused by the environment and not impairment in the body. Mukiza's drive, like that of many teachers with disabilities, is invaluable in implementing inclusive education. They want to change the system to improve educational practices, promote better learning experiences, and make students with disabilities feel better included and accepted in schools and society at large (Duquette 2000; Ferri, Keefe, and Gregg 2001; Dvir 2015; Burns and Bells 2010).

**Interlude: Living Between Hearing and Deafness**

On the International Day of Persons with Disabilities, celebrated internationally every December 3, I sat at a dining table with two deaf women after the national celebratory event organized by the National Council of Persons with Disabilities (NCPD). We were at the Kigali Marriott Hotel, and a lot of delicious buffet-style food and people chatting surrounded us. I introduced myself, and we conversed through a Rwandan Sign Language interpreter. After telling them that I desired to learn Rwandan Sign Language, I publicly disclosed for the first time, “I am partially deaf. I can only hear in my left ear. My right ear is deaf.”

One woman responded happily and welcomingly through her sign language interpreter, “We can teach you. Ask her,” pointing to the Sign language interpreter.

“It took her a few months to learn and over a year of consistent practice to become fluent.”

Another woman added through the sign language interpreter, also smiling, “There is a deaf women’s association, and one is for women who are partially deaf. You should join the organization. Partial deafness is a unique experience that many people do not understand. I think you will like it.”

I was astonished in the best way possible. I could not imagine a better way to ‘come out’ than to warm and proud Deaf women who made me feel acceptable as I am. I did not see pity, awkwardness, shame, or apologies, as is often the case whenever disability is discussed in mainstream culture. For the first time, I felt that being partially deaf was ok, normal, and accepted even though I do not identify as disabled. They affirmed disability as a normal part of human diversity— simply another way of being. I did not have to share much about my experience for them to understand the isolation and loss I felt most of my life because I believed that I was “different.” They encouraged me to join a community with people who shared my

experience. I did not have to hide or whisper about this part of my identity. Deaf people are normal people. There is nothing wrong with Deaf people— in the same way that there is nothing wrong with hearing people.

Much later, I got the courage to share more openly. In the second month of my first semester as a graduate student in Disability Studies, I told my soft-spoken boss (repeatedly) that I was partially deaf and requested him to speak a little louder in meetings— especially when I was in charge of taking minutes. At home, I would be out and about doing random stuff when I would hear my younger brother say loudly, “CATHY! I have been calling you.” Or he would be whispering something to me in secret so our mother could not hear it and repeating himself over and over and over again until he would give me a gentle and questioning look as if to say, “Bruh! How many times am I going to repeat myself?” to which I started replying with a gentle smile, “Man, you know I’m deaf!” And then we would burst out laughing. Hearing people well is still challenging, especially in group conversations when more than one person is talking. Still, I am slowly coming to peace with this part of me and learning to ask for accommodation whenever necessary. I was inspired by stories about disability and deafness written by people with disabilities (including deaf women), and I sought work, such as comedy, by disabled people. One book, “Still Living the Edges,” compiled and edited by Diane Driedger, altered my perception of disability. It helped me to be open and transparent about my encounters with disability in Rwanda and Canada.

I started noticing changes in my social interactions, too. In February 2024, I was hanging out with a bunch of friends in Kigali, Rwanda, when a longtime and dear friend swapped seats with me (without me asking)—and moved to the seat left of me to my “hearing ear”—so I could sit at the top right end of the table to hear the conversations better. It took me by surprise and left

me floored because no one had ever done that for me, and I didn't notice until then that he deliberately sat to my left to accommodate me. Small things like this go a long way in making people feel like they belong. I intentionally use the word belonging here and will return to it in chapter 2. We cannot change certain things about people (for example, deafness, blindness, autism— in my case, not even a hearing aid could help). Still, we can alter the environment or social setups to accommodate people with impairments. It is a matter of figuring out what and how we can change the environment to accommodate people with impairment so they can participate more fully and meaningfully in community life. In the rest of this chapter, I will explore the changes in my understanding of disability during my graduate degree and how they differ and align with the local understanding of disability in the Rwandan community.

### **Individual Models of Disability and the Persistence of Stigma**

My early experiences and understanding of disability were shaped by the individual paradigm of disability, which dominates public policy, services, and attitudes toward disability in Rwanda and worldwide (Oliver, 2004; Shakespeare & Watson, 2002). Growing up in Rwanda, I heard some friends, especially one of my cousins, tell me I was “slow” whenever I repeatedly requested for them to repeat things in conversations. I started believing that I was ‘slow’ and felt ashamed of my ‘bad hearing’. Sometimes, I checked out or avoided big group conversations because I often could not hear what was said. It was uncomfortable and tiring to ask people to repeat themselves and risk being mocked and dismissed. I did not fully embrace nor acknowledge my hearing challenges out loud in conversations until I was twenty-eight. I felt liberated to acknowledge and understand the challenges and the impact they had on me during graduate school (especially reading accounts by disabled women), interacting, and working with

people with disabilities. I realized the years of silence and hiding were costly because they allowed shame to flourish and, to an extent, made me feel unworthy of love and belonging.

As Brené Brown demonstrates in her life narrative about falling in with the wrong crowd in her search for belonging, “Sometimes the most dangerous thing for kids is the silence that allows them to construct their own stories— stories that cast them as alone and unworthy of love and belonging” (Brown, 2010, p. 15). In Rwanda and Canada, where I have spent the majority of my life, disability is shrouded in fear, misinformation, pity, and shame. I still usually get either one of three responses whenever I tell people that I have partial deafness. Some people and my mum (at one point) used to tell me: “No, don’t say that” (with a hit of fear as if saying the word “deaf” out loud would make it true, therefore making me ‘disabled and defective’, which is perceived as one of the worst things that can happen to anyone).

Others, especially in church circles, would say, “Oh no, sorry! I will pray for you.” Other people, like one of my former bosses, were nonchalant or indifferent whenever I asked them to speak louder so I could hear them in meetings, making it extremely hard to take minutes. For some people, it feels more right or kind to ignore it because I have some hearing, and I look “normal.” I used to feel this way, too—just pretend the challenges are not there so you do not have to deal with the discomfort any form of impairment elicits in people. This made me feel alone and alienated. I was sure I was the only one living like this— living in between deafness and hearing— even though there are currently more than 1.5 billion (about 20 percent) people with hearing loss globally ([WHO, 2024](#)).

Additionally, we use euphemisms to avoid and fear any talk about disability because of the discomfort it tends to arouse in people. The Oxford Dictionary defines a euphemism as "a mild or indirect word or expression substituted for one considered too harsh or blunt when

referring to something unpleasant or embarrassing.” Any mention of the word makes people uncomfortable. This comes from the general assumption that the word disability is a dirty, negative, shameful, and embarrassing personal tragedy. It happens everywhere. I was at the hospital in Winnipeg, Manitoba, when a middle-aged, white, Canadian female doctor asked me what I was studying. The nurse to my left was about to give me a shot. The doctor could see that I was anxious and tried to distract me. I responded quietly, “Disability Studies.” She stopped moving and, like the authority figure she was, said, “There is no such thing as disability studies! There are only differently abled people.” I got a visceral reaction— mostly annoyance— but did not say anything in response. I did not have the energy. I simply let her words circle the white rectangular room. I focused on the throbbing pain in my head and arm until it was all surpassed by the burn from the shot.

Euphemisms like this are rampant in disability discourse. So, my earlier fear and discomfort around disability is not surprising, given how grimly disability is discussed in everyday interactions and mainstream culture. In March 2022, a Deaf contestant for the Miss Rwanda pageant was over the news for being part of the contest. It was the first time a person with a visible disability was part of the contest in the fifteen-year history of the pageant, and it drew a lot of media attention. My initial excitement of having a somewhat more diverse group of contestants who represented the diversity of the Rwandan population, including Deaf people, waned with every news story and conversation surrounding her. People were shocked that a Deaf person could be so “eloquent” as she communicated her ideas through a Sign Language interpreter. Most news articles portrayed her as a brave woman who was “defying the odds” and an “inspiration” for doing what other girls her age were doing. For example, a New Times (2022) news article headline read, “Speech and hearing impaired Miss Rwanda contender on braving all

of life's odds." The whole conversation was about what an oddity she was for participating. I heard things like, "Yoo, she is beautiful. It is a pity she is deaf." "Yoo, she is smart despite being deaf." The underlying assumption is that one cannot be disabled, beautiful, and intelligent.

Disability is synonymous with sickness, and the common belief is that people with disabilities are unhappy because of it. These ideas are evident in the language we use when discussing disability. It is common to hear people in Rwanda say, "Yoo," "disi," or "barababaje" when talking about a person with a visible impairment. We tend to use "yoo" or "disi" for unfortunate things; both elicit pity or sadness. Barababaje means sad in Kinyarwanda. I felt annoyed and sapped of energy by the narrative about Uwimana Jeanette and her identity as a Deaf young woman. I was somewhat relieved when I saw a statement from the Deaf community challenging the media to use a person-first narrative instead of focusing solely on her deafness. The Rwanda National Union of the Deaf (RNUD) emphasized her ability as any other contestant— one who used another language, Sign Language, to communicate her ideas— and her right to be judged on an equal basis with others, provided that she is given accommodations such as a Sign Language interpreter at every stage of the contest.

Media coverage of a Deaf Miss Rwanda contestant is a classic example of the common mainstream understanding of disability in Rwanda. The language and words used to describe her journey embody common stereotypes and misrepresentations about people with disabilities in popular culture. Negative attitudes and stereotypes portray Deaf people and other persons with disability as pitiable; a burden; incapable of participating fully in community life; super 'cripples'; objects of ridicule; sexually abnormal; evil and sinister; and objects of violence (Barnes, 1991, Karangwa, 2006, p. 131). These notions are illustrated in the words we use to describe disability and perpetuate the idea that there is something wrong with people who have

impairments. This poses a significant obstacle to the freedom of people with disabilities and their full participation in community life (Barnes, 1991).

Images of suffering and unhappiness are used to portray disability (Barnes, 1991). During a training of community literacy workers on how to accommodate disabled children in reading clubs in Rwanda, several participants argued that having an impairment was a punishment for evil in the family or witchcraft (Save the Children, 2021). One participant summarized it this way, “Having a disability means that the family is cursed or evil or sinned against God, and the disability is just a manifestation of God’s punishment” (personal field notes, 2021). Another person who is active in the disability community said, “We cannot say that a person is living with a disability because living with something implies choice. And no one would choose to live with an impairment/disability” (Ibid). The media perpetuates the same negative stereotypes and distortions, including in advertising campaigns by international and national non-profit organizations.

There is also a widespread belief that disabled people are a burden, which comes from medical explanations that impairment means that, for example, one cannot learn nor be an active and productive member of society. A study by Save the Children International while I was working there revealed that most teachers and caregivers in Rwanda believed that children with disabilities could not learn (Save the Children, 2020). As such, it is not surprising that caregivers do not send their disabled children to school, and those who are sent to mainstream schools tend to drop out early (World Bank, 2023). Caregivers reported sending their children to school on various work field trips, but the head teachers sent them back home. One parent with a child who appeared to have autism told me during Save the Children’s “Back to School Campaign” that her child’s teacher told her to stop sending her to school because she could not learn because of her

impairment. If disabled children cannot learn and become productive members of society, then investing in their education under a utilitarian approach is a waste and a drain on society's resources.

As a result of the chronic misrepresentation of disabled people, there is always a chronic shortage of support services for disabled people. In all my years in the field of inclusion, the issue of budget constraints was always brought up whenever there were questions about the education of children with disabilities. The standing argument is that the educational needs of children with disabilities are profoundly different and more expensive than those of their non-disabled peers. Yet this is not true. Research shows inclusive education is cheaper by 11 percent or 13.5 percent nationally and 37 percent or 41 percent by school district, respectively (Odom et al., 2001; Halvorsen et al., 1996; Salisbury & Chambers, 1994). Furthermore, a study conducted in China revealed each additional year of education for people with disabilities led to a 6.4 percent wage increase (Liao & Zhao, 2013).

The barriers disabled people face, including institutional, physical, communication, and attitudinal, are a direct result of individual models of disability (medical and charity models) for posing disability as a personal deficit or shortcoming instead of as a social responsibility. As a result, people with disabilities are continually required to prove their "neediness," their worth be explained and cured to fit into "normal society." Individual models of disability perpetuate the notion that disability is a personal tragedy and one of the worst things that can happen to anyone (Oliver, 2004; Massoumeh & Leila, 2002; Thoms & Burton, 2015). This perception stems from and is supported by definitions of disability developed by non-disabled people who work for global bodies such as the World Health Organization (WHO). The most widely accepted and used definition of disability in Rwanda and internationally:

Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. (WHO, 2001)

According to the WHO, disability has three dimensions: impairment, activity limitation, and participation restrictions. According to this definition, disability comes from a lack of function and limitations in daily living. For example, Byusa, one of the children I met during my fieldwork, has cerebral palsy, a health condition caused by damage to his developing brain before birth. He has poor muscle development in his legs and arms (impairments in the body). As this condition affects movement and posture, he cannot walk independently and has limited use of his hands (activity limitations). He has never been enrolled in school. According to the medical definition of disability, he cannot attend and participate in school (participation restriction) because of his disability. This definition and distinction between impairment and disability are tricky in the Kinyarwanda language as we have only one word, “ubumuga” for disability and impairment. A disabled person is referred to as “umuntu (human/person) ufite (to have) ubumuga (disability or impairment).”

The medical model works in tandem with the charity model, another long-standing individual view of disability (and in Rwanda with the advent of colonialism). The charity model views disabled people as chronically dependent and passive recipients of assistance from other people, for example, through charitable organizations (Oliver, 2004, 2013). I was at an event when children with disabilities were denied access to the stage to perform an art they had worked so hard to perfect. I later learned through the grapevine that it was because someone or a group

of people on the event organizing team were worried that they “might stop amid the performance and start begging.” This is a common assumption, and people with disabilities can be encountered now and then on the streets of Kigali, asking for money. Medical explanations of disability perpetuate the notion that people with impairments cannot learn nor be active and productive members of society. These meanings individualize and medicalize the challenges associated with impairment, focusing solely on the individual and their perceived inadequacy (Barnes, 2013, 1991).

### **Social Model of Disability**

The prevailing individual paradigm starkly contrasts with the social model of disability. A third model of disability, the social model, emerged in the 1970s as more and more people with disabilities reclaimed their power (agency) for self-definition and self-direction, including defining disability based on their lived experiences (Barnes, 2013, 2004). The social model rejects the sole focus of the individual paradigm and its emphasis on the perceived inadequacy of people with impairment. Instead, it brings attention to the environment and other contextual factors that restrict the full participation of people with impairments in normal community life. It demystifies popular understanding of the experiences of persons with disabilities by challenging the dominant individual models of disability. The term “social model of disability” was coined by Mike Oliver, a British sociologist and disability rights activist who played a crucial role in shaping the understanding of the term (Oliver, 2013). The framework utilizes the concept of oppression to challenge the view that disability is a deficit requiring remedy by experts. It challenges ableist assumptions that privilege non-disabled ways of living and working as the norm by bringing disabled modes of living front and center as it condemns the social production of impairment (Ibid).

While impairment is recognized as the traditional medical approach defines it, the social model defines disability as “the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers” (Barnes, 1991, p. 2). People are disabled by a highly discriminatory society that penalizes people who do not fit nor conform to particular perceptions of normality, not by their impairment (Ibid). Proponents of the social model assess and emphasize the role of economic, environmental, and cultural barriers in disabling individuals (Barnes, 2013, 2004; Oliver, 2013; Shakespeare & Watson, 2002, 2010; Graham et al., 2020). Disability is presented as a human rights and equality issue, and the main objective of the social model is the emancipation of people with disabilities (UN, 2006; Barnes, 2004). The social model was later endorsed and adopted by the United Nations Convention on the Rights of Persons with Disabilities in CRPD in 2006.

Rwandan society, like much of the world, is ableist in that it privileges non-disabled ways of living, and people with disabilities are socialized to occupy an inferior position to other members of society. The inferior position of people with disabilities is socially constructed and backed by an ideology that justifies and perpetuates their disadvantage (Abberley, 1987). According to Abberley (Ibid), historical analysis is necessary to understand the situation of disabled persons today. To understand disability today requires an examination of the differences between the lives of disabled people, non-disabled people, and other oppressed groups. This examination involves “question[ing] old ideas about disability, development, and western colonization, nine-to-five rushed lives, and building [platforms] to unite people with disabilities around their common experiences” (Driedger, 2021, p.12). Reading historical documents on the development of disability and social changes through the ages, particularly during the European

colonial age, through one of my graduate courses cemented my understanding of the social theory of disability as oppression.

### **Social Theory of Disability as Oppression**

The concept of oppression helps us understand a social theory of disability. Barnes argues that the term “‘disability’ represents a complex system of social restrictions imposed on people with impairments by a highly discriminatory society. “To be disabled... means to be discriminated against” (Barnes, 1991, as cited in Abberley, 1991, p. 2). He lists five key features of oppression (Abberley, 1991, p. 17). First, it is specific in form, location, and content. It is easy to see when we identify the differences between the lives of people with disabilities and other aspects of life, including other oppressed groups. Second, people with disabilities as a group occupy an inferior position to other members of society “by virtue of belonging to that group” (Ibid). Third, the disadvantages are “dialectically related to an ideology or group of ideologies which justify and perpetuate this situation” (Ibid). Fourth, the disadvantages and their supporting ideologies are not natural or inevitable. Finally, this state of affairs has a beneficiary, and they can be identified.

As discussed earlier, medical ideology devalues the impaired modes of being while naturalizing the causes of impairment (Abberley, 1991). The social theory of disability as oppression allows us to organize together into a coherent conceptual whole “isolated and disparate areas of social research, and potentially to correct the results of such theoretical myopia” (Ibid, p.17). This view aligns with the feminist definition of oppression as a systemic web of various barriers and forces that intersect and interact to shape the lives of women and other marginalized groups (as explained in the introduction). Systemic oppression is evident in

the historical development of disability, and it has profound political implications and conceptual consequences on the education of children with disabilities today.

### **Intersectionality in Disability Studies**

“If you see inequality as a “them” problem or “unfortunate other” problem, that is a problem. We have got to be open to looking at all the way our systems reproduce inequalities, and that includes the privileges as well as the harms” ~Kimberle Crenshaw (Time, 2020)

Disability studies have also evolved to incorporate intersectionality to acknowledge the interconnected nature of social identities and systems of oppression. Intersectionality in disability studies shows that people with disabilities may face multiple forms of disadvantage and discrimination based on myriad factors such as race, gender, disability, class, nationality, and other identity markers. Therefore, applying an intersectional lens allows for recognizing how these identities shape unique experiences of disability and influence access to opportunities, rights, and resources. This means that there is a diversity of experiences even for children with disabilities, for example, autism. According to Kimberle Crenshaw, a civil rights activist, lawyer, and professor who coined the term intersectionality in 1989, it is a “lens, a prism, for seeing how various forms of inequality based on gender, class, sexuality, or immigrant status” (Time, 2020).

In a recent Time interview (2020), Crenshaw re-elaborated what intersectionality means today after over thirty years since she coined the term. She emphasized that there is still much need to continually assess where power comes and collides and shapes people’s experiences. Some people are subject to all forms of oppression, which operate together and amplify each other, causing more marginalization and discrimination that is more than the sum of its parts (Crenshaw, 1989). People with disabilities, women in rural areas, young girls, and refugees, for example, are the most impacted by poverty and crises. Girls with disabilities are both disabled

and girls and, therefore, subject to discrimination based on their disability and gender. Structural inequalities shape their lives. Therefore, intersectionality provides a framework through which we can name, challenge, and root out all forms of oppression to build an inclusive society free of discrimination and fair for all (UN WOMEN, 2020). To build a future that leaves no one behind, we need to examine and understand how multiple interlocking identities create unique experiences and vulnerabilities.

In the education sector, disability studies prioritize the right to education of all learners, particularly learners with disabilities. As a result of the above advancements, disability studies provide a more comprehensive understanding of disability, promoting inclusive policies and practices that empower and respect the rights of persons with disabilities.

### **Historical Analysis**

#### **The Evolution of Disability**

Time-specific processes produced and reproduced the racial ‘other’ and disability. This is evident in historical accounts of disability, particularly the way disability took on a new social meaning during the European colonial expansion in the eighteenth century. Esme Cleall (2015) writes a compelling article about this on deafness. In “Orientalising deafness: race and disability in Imperial Britain,” Esme Cleall uses a historical perspective to examine the origins and implications of the intersection between race, colonialism, and disability by focusing on how deafness was reconfigured in nineteenth-century imperial Britain. Disability as a social category intersects with and is shaped by other categories of difference, such as race and gender, based on specific situations, relationships, and power dynamics. By framing this discussion in a colonial context, Cleall reveals how various forces and processes of racial and imperialist

disenfranchisement inscribed new social meaning to bodies of particular groups of people and thereby shaped social understanding of disability and the racial 'other.'

Deafness was created through an ideology from a particular tradition of thought, imagery, and vocabulary tied to British imperialism and its empire. Sociocultural changes in eighteenth-century and nineteenth-century Britain and its colonial empire influenced the construction of Deafness and affected deaf people in Britain and the colonies. From the eighteenth century, representations and portrayals of the colonial 'other' were produced and set up against an imagined norm to justify colonialism, exploitation, and violence. In this environment, as issues of race and empire gained increasing levels of cultural dominance fueled by political ambitions to dominate racialized people in South Asia, Africa, and Australasia, social attitudes towards disability also shifted to carry similar connotations and stigmatizing beliefs. Disability, like race, is a marked difference inscribed on the body that did not fit the normative subject defined at the time as white, European, and non-disabled.

Deaf people, for example, did not fit the description of a "normative subject" and were described through reigning ideas about medical or physiological 'deformity.' Ideas around difference were used to colonize racialized others, which also created a broader shift in what constituted a 'normative subject.' At the same time, Deaf people began to be identified as a biological category (a deaf race) and as a cultural group (deaf heathens). Oppressive apparatus like the one employed in the colonies was used to control deaf people in Britain because they were considered an 'inferior race' lacking in intellect ('backward,' 'animalist,' in the 'original state') and language and therefore in need of saving, civilizing, and Christianizing. Deaf people were portrayed as 'diseased,' 'animalistic,' and inferior because of their embodied identities.

These changes were institutionalized through the law, policy, education, and religion and were solidified by Western science, especially the medical profession.

In Cleall's words, "disability and disabled people always represent what is 'unlike,' what 'should not exist' or what must be assimilated" (Cleall, 2015, p. 24). Deaf people, like the racialized 'other' in Britain's colonial empire, were engineered through the law, policy, education, and religion to occupy an inferior position to other members of society for the benefit of the British state. The institutionalization of the inferiority of disabled people was done through laws such as the 1834 Poor Law Amendment Act, which objectified disabled people as the 'deserving poor' (Cleall, 2015). From the nineteenth century, people with disabilities were institutionalized and put away in asylums and residential schools. Education policies were passed to privilege oralism and required that deaf children be taught spoken and written English. The use of Sign Language by Deaf people was used to emphasize their religious otherness, thus employing pseudo-scientific ways to prove their inherent peculiarity.

More specifically, the advancements in science in the eighteenth and nineteenth centuries increased the authoritative position of medical professionals (hence the rise of the medical model of disability). Scientific advancements gave medical professionals the power to define 'normal' or 'abnormal.' This had dire consequences for people with impairments, as those who were deemed abnormal were eliminated through eugenics or declared ill-fit to participate in society unless cured and for care through goodwill and pity. Scientists such as George Combe and Edward B. Tyler went to extreme lengths to prove through scientific investigation—that is, prodding bodies of deaf people and racialized 'others' (such as Sarah Baartman, who was stolen from her home and paraded around Europe for her apparently 'deformed body' because she was a black woman)—that they were primitive, evil, and burdensome members of society.

However, while deafness was orientalized in Britain, deaf people do not occupy the same social position and power. Deaf people in Britain occupied, supported, and benefitted from the British imperialist system in a way that the racialized disabled ‘others’ in Britain’s colonies did not. Edward Said coined the term “orientalism,” which refers to the patronizing body of scholarship and attitude toward Eastern cultures and people of the “Orient” by the West directed toward people in the West (Said, 1978). The “Orient” (East) and the “Occident” are man-made and, therefore, as shown above, rooted in a particular history. This history is marked by a relationship of power and domination whereby Europe and later America created a body of theory and knowledge about the “Orient” as an inferior ‘other’ of Europe, giving it reality and presence in and for the West. Deaf people in Britain employed the language of the oppressor when talking about racialized others in the colonies. Their whiteness allowed and still allows them to occupy a position that their non-white and deaf counterparts in the colonies would not be permitted at the time and to this day.

Therefore, it is important to recognize the history of unequal power relations within the movement to liberate people with disabilities. While disability is common and exists in all cultures, it is not a uniform experience, and disabled people can and, in some cases, have contributed to the disenfranchisement of other people with disabilities. Non-disabled white men and some disabled white people mostly led colonization. Deaf people like Francis Baring and Francis Humberstone Mackenzie were involved in the slave trade and gained vast amounts of money and prestige as a result. Mackenzie, a deaf white man, was the Governor of Barbados for over six years (1800 to 1806). In the next sect, I will explore how the meaning of disability and the lives of people with disabilities were affected by colonialism and its “civilizing” mission in Rwanda.

**Interlude: “Deaf Out Loud”**

In *Deaf Out Loud*, Joanna Hawkins, born to Deaf Polish parents, narrates the heartbreak and barriers she encountered when she became Deaf at three in 1984 due to an ear infection. After her parents (certified engineers) were forced to leave Poland due to changes to labor union political agreements, which made it hard to find employment, her paternal grandmother banned her from using Polish Sign Language because “it was not a real language” but “a disgusting form of gesture that made us look dumb” (Hawkins, 2022, p. 15). Her grandmother, who she lived with for several years, did everything to ensure that she communicated orally, including going to a mainstream school, wearing hearing aids (which were uncomfortable and children made fun of), and taking speech therapy every week to sound right.

This was exhausting for Joana, and she likened her day of lip reading while sitting in the front row at school to “reading five books every day” (Hawkins, 2022, p. 15). With all the efforts put into making her speak and read lips fit into the auditory world, she still had minimal access to information, missing 80 percent of the background information. Consequently, she felt like “an ugly duckling” who did not belong (Ibid). People were scared of her because she was Deaf. Additionally, when she enrolled at the University of Manitoba sometime in the early 2000s, her student advisor denied her from majoring in the performing arts because she was deaf. “Fortunately,” she is now fulfilling her acting dream (inspired by watching the pantomimes of Mr. Bean and Charlie Chaplin on TV) while also working with a disabled people’s organization supporting families of children with Deaf or hard-of-hearing children in Winnipeg. But many Deaf and Hard of Hearing children are not so fortunate, especially those who are born to poor parents in rural Rwanda. They come up against similar barriers and do not make it on the other side as winners pursuing their dreams full throttle.

As I read Joana's story in my Women and Disabilities class, I felt a sense of pride and joy. I was glad that she reunited with her Deaf parents in Canada because it allowed her to be Deaf out loud and gain a sense of identity as she ventured into the world. She faced obstacle after obstacle and still managed to make her way to a life she loves, including acting and supporting families with Deaf children. Later, when I was told that my young cousin was partially deaf and struggling to live with that revelation, I had a good story to refer back to— a real story of breaking barriers and glass ceilings. Their stories are not similar, but I could confidently draw on stories of disabled women like Joan and others to reassure her that she could still live the life of her dreams and on her terms, too. I have to do that because she felt and believed otherwise because of school bullies and the mixed messages from a disability-unfriendly world.

### **Reclaiming Traditional Rwandan Values of Inclusion**

Current understandings of disability and formal education in Rwanda can be traced back to colonialism and Edward Said's concept of Orientalism (1978). Systems of oppression, including colonial oppression, are woven into our culture, society, and laws. Oppression can be experienced through limitations, disadvantages, or disapproval. Social institutions, such as education, government, and culture, contribute to or reinforce the oppression of marginalized groups while elevating dominant social groups. Our social identities carry characteristics that bestow power, privileges, or disadvantages. They can explain differences in outcomes, effort, or ability and are difficult to change. In this section, I employ a postcolonial theoretical lens to re-examine an influential historical article in my understanding of disability as oppression and show how systems of oppression work to disadvantage people of marked social identities, for example, Deaf people in imperial Britain. Historical analysis reveals how continuities from the past

continue to shape the present situation of people with disabilities in Rwanda. Furthermore, it also shows how disability comprises all five features of oppression.

A close examination of Rwanda's history reveals the advent of special education for children with disabilities in Rwanda during colonialism and marks the beginning of segregation and current discrimination against persons with disabilities in Rwanda. Before colonialism, persons with disabilities belonged and were accepted in their communities. The colonial emphasis on the medical and charity models of disability laid the foundation for discrimination, prejudice, and stigma that persists today. This marks a departure and difference in my understanding of disability in Rwanda from my local understanding. Therefore, a path to address present inequalities in access and education outcomes needs to unpack colonial legacies to reimagine an education system that is founded on traditional Rwandan values of inclusion founded on principles of solidarity, community engagement, and the inherent dignity of every member of the community.

### **Postcolonial Theory**

In the context of disability and education in Rwanda, postcolonial theory helped form my understanding. It helped me consider how and where to begin to address the social aspects of disability and educational inequalities. Postcolonialism is “a cultural, intellectual, political, and literary movement of the twentieth and twenty-first centuries characterized by the representation and analysis of the historical experiences and subjectivities of the victims, individuals, and nations of colonial power” (Fajardo-Acosta). Two key characteristics mark it: 1) resistance to colonialism and, 2) the “attempt to understand the historical and other conditions of its emergence as well as its lasting consequences” (Ibid). By framing the discussion about disability and the treatment of disabled people today in a colonial context, we see how various forces and

processes of disenfranchisement inscribed new social meaning and identities to bodies of particular groups of people and thereby shaped today's mainstream social understanding of disability and the racial 'other.'

### **Rwandan Culture: “Kubaho nu Kubana”– “to be” is “to be with”**

The current understanding of disability in Rwanda is a historical development created and recreated through a particular tradition of thought, imagery, and vocabulary/words. This is evident in the ongoing changes in the larger Rwandan society, which are related to the education and inclusion of persons with disabilities in community life. In 2012, the government of Rwanda passed a national childcare reform to end the institutionalization of children in Rwanda, which started in 1954. As a result of this reform, over 91 percent of children have been reintegrated with their families, with most orphanages turned into community hubs (Hope and Home, 2023). A similar policy in education was revised in 2019 for the full inclusion of children with disabilities in the Rwandan mainstream education system. These policies align with the Ubuntu philosophy upon which traditional Rwandan values of inclusion can be traced back to before colonization and the formalization of education and segregated schools.

In the Rwandan context, community means physical and psychological environmental attributes that bind people together (Karangwa, 2006). Earlier studies by Kagame (1954, cited in Karangwa, 2006) and Nothomb (1965, cited in Karangwa, 2006) reveal that humanism and solidarity characterize the Rwandan grassroots community. This community of 'Ubumwe' or 'Solidarity' is informed by cultural values such as the concept of 'Kubana' or 'to live with.' In this case, to live or 'kubaho' is to live with others within 'Umuryango' (Nothomb, 1965, cited in Karangwa, 2006, p. 20), or wide family unit, and 'inzu' or clan. The sense of community extends beyond immediate family relations and includes people with common interests and identifiable

geographical residential locations (Karangwa 2006, p. 20). This is articulated in the following observation by Nothcomb in his earlier studies of the Rwandan culture:

Man [and woman] in Rwanda is not an island. He is much more than just an individual. 'To be' or 'kubaho' for him is 'to be with' or 'kubana'... that aspect of his life is only a minor phenomenon with much more fundamental humane values, expressed as "ubumwe." (Nothomb, 1965, p. 148, cited in Karangwa, 2006, p. 21)

While Nothcomb's definition uses sexist language (man as a representative of all human beings), the community is described as a sense of belonging, the extent to which one feels part of a dependable social structure. Community participation and having a felt sense of belonging to a community is associated with better quality of life for young people with disabilities (Branston et al., 2002, cited in Karangwa, 2006; Brown, 2017).

The humanism articulated in the passage above is pervasive in Rwanda and most parts of Africa and is integrated into everyday life. It stems from the belief in group solidarity, which is central to the survival of African communities and is commonly known as Ubuntu amongst people of Bantu origin in Southern, Central, West, and East Africa (Rwelamila, Talukhaba & Ngowi, 1999, p. 338). Ubuntu is derived from a Nguni (isiZulu) aphorism: "Umuntu Ngumuntu Ngabantu," which can be translated as "a person is a person because of or through others" (Moloketi, 2009, p. 243; Tutu, 2004, p. 25-26). The philosophy of Ubuntu can also be expressed in the phrase: "I am because We Are." Furthermore, the practice of the Ubuntu philosophy necessitates individuals to express compassion, reciprocity, humanity, and mutuality as a way of life (Mandela, 2006, p. xxv). The strength of the community is deeply rooted in Rwandan culture. As such, community involvement and solidarity have always played a vital role (in an

inclusive way) in responding to the needs of disadvantaged members of society, including persons with disabilities.

### **Segregation of Children with Disabilities in Education**

Children with disabilities in Rwanda first got access to formal education through a segregated education system founded on the charity and medical models of disability. To this day, most persons with disabilities who are educated or children with disabilities who are in school go to special or segregated schools. Special schools in Rwanda are private and, in most cases, founded and run by charities. The first segregated school, Home de la Vierge des Pauvres (HVP) Gatagara, for children with disabilities was established in 1962 by Fr. Joseph Fraipont in present-day Nyanza District in the Southern Province of Rwanda (Karangwa, 2008, 2013, 2014). When HVP was first established, it provided full-time care to children with visual and physical disabilities until the end of primary school, after which they were sent back to their respective villages. The establishment of HVP Gatagara marks the beginning of the formal education of children with disabilities but also the beginning of their institutionalization, segregation, and the infiltration of Western ideas, attitudes, and discriminatory practices against persons with disabilities in Rwandan culture (Karangwa, 2014).

However, the education of children with disabilities remained limited for a long time compared to their non-disabled peers. It was not until 1997 that G.S Gahini, a mainstream secondary school, opened its doors, and students with disabilities first got access to secondary education. Then, in the early 2000s, HVP Gatagara Nyanza opened two more branches in the Huye and Rwamagana districts. Finally, in 2011, after many years of advocacy by different organizations for persons with disabilities and the leadership of Professor Evariste Karangwa, students with disabilities were officially granted access to Rwandan universities (Karangwa,

2014). Following the establishment of HVP Gatagara primary school for children with visual and physical disabilities, over fifty special schools have sprung up over the years to educate children with disabilities using a similar model of care founded on the medical and charity model of disability (Karangwa, 2008).

Today, most special schools specialize in caring for children with particular kinds of disabilities, and most are boarding schools, providing full-time care to their students (Karangwa, 2014). A medical approach is used for admitting new students, as guardians must provide medical proof/certificate of a child's disability and school tests. These private schools are inaccessible to most guardians who cannot afford school fees or find a sponsor. So, access and participation of children with disabilities in education remains restricted compared to those without disabilities (35 percent and 19.3 percent, respectively) due to various barriers to learning and participation, including physical and attitudinal barriers. Barriers are hindrances or obstacles that limit the active participation of persons with disabilities in the learning environment.

According to Booth and Ainscow (2002, p. 5), "Barriers may be found in all aspects of the school, as well as with the communities and in local and national policies. Barriers also arise in the interaction between students and what and how they are taught". There are "barriers to doing" and "barriers to being" (Cologon, 2014). Barriers to doing include environmental and economic barriers, which are socially enforced, while barriers to being are "inappropriate, hurtful, or hostile behaviors that hurt an individual's sense of self, thus affecting who or what an individual feels s/he can be" (Cologon, 2014, p. 38).

\*\*\*\*\*

## **Chapter Two**

### **Transforming Perspectives on Inclusive Education**

“Not merely an aspirational moving target or rhetoric, equity science asserts equity as a benchmark is an urgent, viable, and plausible goal for all efforts in [education].” (Plamondon and Shahram, 2024, p. 4)

This chapter opens with my epiphany about the transformative power of education to create an equitable and inclusive society. I explore how my understanding of disability inclusion, as something that comes from values of equity science (and reflexive praxis), influenced my professional choices and perspective on implementing inclusive education in Rwandan schools for liberation and belonging. As such, my professional choices emphasize the need for equitable resource allocation, fostering a sense of belonging through authenticity and collaboration with persons with disabilities, and leveraging critical praxis. I argue that using a transformative approach to education rather than a utilitarian one is the key to challenging systemic barriers and advancing inclusive education for children with disabilities in Rwanda.

#### **The Transformative Potential of Education**

One day, while researching for my thesis, I accidentally came across a quote from 1848 by Horace Mann on the internet, "Education, then, beyond all other divides of human origin, is a great equalizer of conditions of men—the balance wheel of the social machinery." It was a big “Aha moment” as it crystallized my professional pursuit. Education has always been, for me, a liberating and transformative practice. I have learned the necessity and possibilities of living by one's values and dignity through engaging with the world critically. But the quote by Mann left me with many questions as it illuminated my pursuit of equality and creating an equitable world.

Is education really “a great equalizer of the conditions” of women and men in our current neoliberal and globalized world? Has education ever been a “great equalizer,” given the rising global inequality and power imbalance between the global North and South? In “Pedagogy of the Oppressed” (1970), Paulo Freire argues that yes, education is not only a great equalizer but also the only means through which marginalized peoples or “the oppressed” can free themselves and their “oppressors.” I use Paulo Freire’s argument to frame my discussion about implementing inclusive education in Rwanda. For inclusive education to bring real change and remove existing inequalities, it must be designed to eliminate oppression through dialogic action, including 1) consciousness-raising (reflection on the nature of oppression) and 2) taking concrete action to transform it.

### **Tensions between Utilitarian and Transformative Frameworks in the SDGs**

Rwanda has been implementing some form of formal education as we know it today since colonial rule under German and, subsequently, Belgian rule. Most of my work in Rwanda with international development agencies (2019 - 2023) was particularly defined by Sustainable Development Goal (SDG) 4, which aims to “ensure inclusive and equitable quality education and promote lifelong learning opportunities for all.” Rwanda’s education plans and goals mirror the language of the SDGs, which points to the larger education context of neoliberalism and globalization, where knowledge is considered essential to successful participation in a productive society. Rwanda’s Education Strategic Plan (ESSP) 2018/19-2023/24 was developed following “global, regional and national development agenda for Sustainable Development Goals (SDGs) with the goals of:

promoting access to education at all levels, improving the quality of education and training, strengthening the relevance of education and training, all aligned to meet labor

market demands. Equity in access and quality of education is emphasized across all three goals to ensure that the disadvantaged, the poor and children living with disabilities, have access to meaningful learning opportunities (Ministry of Education 2018, i– emphasis not mine).

SDG 4, as echoed in Rwanda’s ESSP 2018/19-2023/24, is framed within two dominant approaches to education, including the utilitarian and transformative frameworks.

A utilitarian approach “portrays education as a social investment designed to ensure that succeeding generations are able to assume their place as productive citizens within an established socio-economic order” (Maclure et al., 2009, p. 367). The rationale for the utilitarian view of education is that education will result in a productive citizen who will contribute to the economic growth and development of the nation. A child, therefore, is educated for the labor market– in other words, to sustain things as they are. This approach is problematic, especially regarding educating people who may not necessarily fit into the confines of a desired “productive citizen” as determined by the current neoliberal labor market system. Harvey (2005) defines neoliberalism as “a theory of political, economic practices that proposes that human well-being can be best advanced by liberating individual entrepreneurial freedom and skills with an institutional framework characterized by property rights, free markets, and trade” (p. 2).

Within this environment, which is highly globalized, the notion of “sustainable development” is also problematic because “everything in the neoliberal system, including education (as elaborated above), is subjected to market dynamics, not social and environmental development” (Mitter, 2016). Globalization is described as “A set of processes by which the world is rapidly being integrated into one economic space via increased international trade, the internationalization of production and financial markets, and the internationalization of a

commodity culture promoted by an increasingly networked global telecommunications system” (Gibson-Graham, 2006, p. 121; Lang, 2006). The ultimate goal of neoliberal education in this environment is to enhance economic growth and productivity; it is not liberation from oppression.

The transformative approach to education, on the other hand, holds different values from utilitarianism, including values of equity and justice. Education is viewed “as a force for liberation, encouraging learners to regard the world critically and acquire skills and aptitudes necessary for generating fundamental change” (Maclure et al., 2009, p. 367). Yet, the SDGs and Rwanda’s education plans and policies intertwine the utilitarian and transformative approaches in a way that does not challenge already established power dynamics in the global and national school system. Therefore, our current education system in Rwanda is not designed primarily to address inequalities and injustices. As Maclure et al. have argued, the transformative education rhetoric only depoliticizes the concept of educational change as long as it upholds the utilitarian view of education (Ibid). The values of the market far outweigh the values of social and environmental development. Against this backdrop, I began to slowly and quite obsessively wonder how and what a transformational education would look like for some of the most marginalized children, including children with disabilities in low-income, formerly colonized African countries such as Rwanda.

### **Inequality in Education: Where are Children with Disabilities?**

When I got my first job in the international development at Save the Children, I wondered how children with disabilities were faring and accommodated in different donor-funded projects, particularly in education. I quickly learned that there was little to no inclusion of children with disabilities in most projects. International data from UNICEF (2021) shows that

there are approximately 240 million children with some form of disability worldwide currently out of school. Furthermore, 49 percent of children with disabilities worldwide never attend school; they are 24 percent less likely to receive early stimulation and responsive care, 42 percent less likely to have foundational reading and numeracy skills, 25 percent more likely to be wasted, and 34 percent more likely to be stunted, 53 percent more likely to have symptoms of acute respiratory infection, and 51 percent more likely to feel unhappy and 41 percent more likely to feel discriminated against (Ibid). Their chances for developing essential foundational reading and numeracy skills are significantly lower compared to children without disabilities.

Statistics from Rwanda's Ministry of Education show zero point eight percent of the primary school population are children with disabilities, and merely ten percent of all children with disabilities are enrolled in school (ESSP 2018/19-2022/23; Ministry of Education, 2016). Additionally, the quality of education for children with disabilities is a concern, with high dropout rates (27 percent of children with disabilities drop out compared to 14 percent of children without disabilities) and poor performance compared to their non-disabled peers (65 percent of children with disabilities compared to 81 of children without disabilities) (RHPC, 2022; Mutezigaju, 2019; Bots, 2015; Mattingly & Suubi, 2015). Inclusive education has been presented since the early 1990s as the answer to removing education disparities between children with disabilities (among other marginalized groups) and their non-disabled peers. The rest of this chapter will explore the idea of inclusive education and its implementation in Rwanda. But first, what does the concept of "inclusion" mean? What do we mean when we say that something is "inclusive"?

### **Interlude: My First Inclusion Job in Canada**

Linda: “Hello. Linda is speaking. How may I help you?” said a female voice at the other end of the line.

Cathy: “Hello. I am Catherine Batamuriza. I love children and am currently looking for a childcare job. Are you hiring?” I responded to the person on the other end of the line as I nervously held my breath. It was the third daycare I had cold-called in my job search. Summer was fast approaching, and I needed to get a job. It is a plus if it is in childcare.

Linda: “Hi Catherine, Uuhm, sorry, I don’t think so. Is this your number? We can contact you when something opens up,” Linda replied.

Cathy: “Yes, this is my phone number, and that would be great. Thank you, Linda. Have a great day,” I said.

Linda: “OK. You are welcome. Have a lovely day, and all the best. Bye,” responded Linda before hanging up.

I said bye and hung up the phone. A few seconds later, my phone rang again, and I jumped up to pick it up. It was an unsaved number. I had applied to several places, so maybe it was a potential employer.

Cathy: “Hello.”

Linda: “Hi, Catherine. It’s Linda again. Sorry, someone here reminded me that we are hiring an Inclusion Support Worker. Would that be of interest to you?”

Cathy: “Hi, Linda. Yes, absolutely. I would be interested in the role,” I say as I walk to my desk and jot down in large block letters: **INCLUSION SUPPORT WORKER JOB DESCRIPTION.**

Linda: “Perfect! Can you send us your resume and please copy Brenda? If that is OK with you, we can schedule an interview for next week,” said Linda before telling me their email addresses.

Cathy: “Certainly, I will do it right away. Thank you so much, Linda.”

Linda: “Awesome. We look forward to talking to you. Jane will contact you shortly regarding the interview date, time, and location. Ok?” I could hear her smiling on the other line as we spoke.

Cathy: “Sounds great. I look forward to talking to you, too.”

Linda: “Ok, thanks, Catherine. Bye.”

After I hung up, I jumped up and down joyfully and quickly got down to business. In Google, I type: “WHAT IS THE JOB DESCRIPTION OF AN INCLUSION SUPPORT WORKER?” It was the first time I heard about the role, and I did not quite understand it. But I was determined to become ‘an expert’ at whatever it was before my interview the following week. I was an undergraduate student majoring in Global Political Economy at the University of Manitoba and had worked part-time at different malls as a ‘sales associate.’ I liked to tell my friends and family in Rwanda that my job title was not as fancy and lovely as it sounded because they usually exclaimed, “Wow!” whenever I told them what I did. I told them it was a title Canadian employers give underpaid and overworked people in retail stores—mostly young university or high school students— to fold clothes, mop floors, sometimes run cash transactions, and continually feed the capitalist dragon by manipulating people/’consumers’ to buy more than they need so as always to exceed yesterday’s sales and make more profits for the wealthy one percent. I hated the retail job so much.

The Daycare Center called me back to schedule an interview a few days later, and I had four days to prepare. I read everything I could find as I continually reminded myself that Maya Angelou worked a bunch of random jobs as a young single mother, such as a fry cook, a cast member in an opera, an actress, a nightclub performer, a Southern Christian Leadership Conference coordinator, a correspondent in Egypt and Ghana. If she could do all that without prior experience, I could pull this off, too. I also read Maxwell Maltz's book *PsychoCybernetics: Updated and Extended* (2015) and used visualization to see myself as an Inclusion Support Worker, performing all my tasks effortlessly. I believe Maxwell's book was pivotal in my getting the job. Otherwise, the lack of experience in the role and major imposter syndrome would not have allowed me to 'prosper in peace.' I got the job and, for the next two years, worked one-on-one at different times with children on the autistic spectrum disorder (ASD) and briefly with a child with attention deficit hyperactivity disorder (ADHD).

\*\*\*\*\*

## **The Evolution of Inclusive Education and the Need for Equity**

### **The Concept of Inclusion**

I first joined the field of disability inclusion in Canada in 2017. I did not know what it fully meant, and much of what I did was learned on the job. I felt so insecure. The only thing that gave me the courage to dive into what felt like the deep end (with minimal specialized skills in how to support an autistic child) was my love of and for children: it is my second love—right up there next to God. When I first moved to Canada as an undergraduate student, I had to fight hard not to come off as “creepy” because of my instinctual pull to care for children. In Rwanda, I did not have this problem as, for the most part, it is socially acceptable for adults and others to interact with children in the community. It is common for adults to randomly give unsolicited

advice and feel obligated to care for children that they may not be biologically related to. Random people can easily reach out adoringly to carry someone's child, talk to them, or admonish them when they misbehave (especially outside Kigali). There are not as many associations of strangers and danger as in Canada. But alas, I learned to adjust to Canadian society. Working directly with two children and one indirectly (she was in the center, but she did not need one-on-one support) on the autistic spectrum disorder (ASD) was my first introduction to disability inclusion in a childcare setting—albeit in a school environment. The early lessons I learned there continue to inform and sometimes conflict with my current understanding of inclusion and what inclusive spaces look and feel like.

The word inclusion has gained popularity in the education sector in recent years through international treaties, but the term still needs to be clarified (Ainscow, 2020, p. 9; Pellicano et al., 2008). It tends to mean or elicit different things to different people and is a cause for debate worldwide. The Cambridge Dictionary defines inclusion as “the fact of including someone or something as part of a group, list, etc., or a person or thing that is included” and in education specifically, as “the idea that everyone should be able to use the same facilities, take part in the same activities, and enjoy the same experiences, including people who have a disability or other disadvantage.” Its etymology dates back to 1600 as the “act of making part of,” from Latin *inclusionem* (nominative *inclusio*), “shutting up, confinement,” noun of action from the past participle stem of *includere* (Oxford English Dictionary, 2024). Its meaning as “that which is included” was first noted in 1839 (Ibid). Mel Ainscow, who has done much work on inclusive education, argues that inclusive education is about creating a regular or mainstream environment where everyone can participate fully in all aspects of school life (Ainscow, 2020).

Ainscow's definition aligns with that provided by the United Nations, where inclusion is "a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences" (United Nations, 2016, p. 4). Accordingly, inclusion involves designing spaces, activities, and programs to accommodate and respond to the uniqueness and needs of all, including persons with disabilities, so that they can participate fully and meaningfully alongside their peers without disabilities. Autistic spectrum disorder (ASD), for example, presents differently in everyone, so that needs may vary from one person to another. It is classified as a lifelong neurodevelopmental disability (Christopher, 2019; Critz et al., 2015). There is no one cause of autism. Multiple factors, including genetics and environment, can contribute to its development (Critz et al., 2015). The diagnosis refers to individuals who meet a specific set of criteria in social communication and restrictive/repetitive behaviors across the severity spectrum (American Psychiatric Association diagnostic manual). The criterion tends to be deficit-based and may not best represent the wide range of autistic experiences.

People with autism have unique experiences (like all people) and complex and ever-changing lives (Christopher, 2019; Critz et al., 2015). Autism is a spectrum, just like a wheel (Ibid). I worked with two siblings with autism in my first two years of employment, and each had unique traits, strengths, and challenges in different areas. They had key characteristics of autism in different areas, including social interaction, cognition, communication, sensory, and behavioral. One autistic child was verbal, while the others were not. John, for instance, loved and obsessed over numbers, the alphabet, and sorting things in a certain way. He could solve

advanced math problems that other children his age could not. Brianna, on the other hand, was more laid back in her engagement and interaction with objects and people and was quiet for the most part (except when expressing emotions such as laughing and crying). These nuances are important to highlight, so we are not trapped with a unidimensional negative view of ASD, or any other disability, as it is often presented in the media.

I find the concept of neurodiversity helpful in understanding autism in a way that is more accepting of our differences as people in general. Neurodiversity describes autism as a condition or identity related to neurodevelopment (Baumer & Frueh, 2021). Our brains as people are different, meaning each person processes information differently (Ibid). So, the concept celebrates and embraces these neurodevelopment differences rather than classifying atypical differences as disorders (Ibid). Furthermore, within my first six months of employment, I learned that understanding and accommodating individual children's needs is essential to ease discomfort and increase children's opportunities to learn, socialize, communicate, and participate in group activities. Autistic children can experience hypersensitivity and hyposensitivity to stimuli (Critz et al., 2015; Christopher, 2019). Hypersensitivity is related to over-responsiveness, while hyposensitivity means under-responsiveness to sounds, sights, smells, tastes, touch, balance, proprioception, and interoception (Christopher, 2019). Brianna had hypersensitivity to sounds, so we had earphones for noise cancelation and closed doors in the center, and his parents chose a diet that worked for her tastes. She also had hyposensitivity issues, so we had visual supports for communication, such as fidget toys and chewies, and arranged furniture in an open, safe, and child-friendly manner.

Controlling the physical environment is key to learning and growth for all learners, especially learners with disabilities (Christopher, 2019). The physical and social environment

can enhance or add new traits linked to autism, so different supports and understanding are important to accommodate children with ASD fully (Critz et al., 2015; Christopher, 2019). This was especially obvious when we went on field trips, as certain autistic traits were more pronounced because there were so many stimuli (sounds, smells, objects) that we had limited control over. We could not avoid field trips or leave children with ASD because “they were difficult.” We learned from every experience and used it to better prepare for the next one (especially since we did only about three to four field trips a year). This points back to the critical need for resource equity (as described in the introductory chapter) to ensure that all the needs of children with disabilities are accounted for in education and other sectors.

### **Interlude: Supporting Children with Autism**

It was a sunny day outside. It was not too hot. I am unsure if it was the mix of children’s voices playing on the play structure, the sight of bubbles floating in the air, and birds chirping around me, but I felt at home and full of hope. It was my first week at the daycare, and I was anxious to do a good job. I stood in motion and on full alert with a smile plastered on my face as I watched Steve spin around in circles while he sucked on his thumb. Occasionally, he would stop, flap his hands, and laugh. I would copy him many times, but I did not spin. I later learned at a workshop on autism that these were self-stimulating behaviors that help people with autism keep their sensory system in balance and avoid sensory overload or burnout. Indoors, he would often sit in a green rocking chair while moving back and forth and frequently intentionally crash into things (we kept the toys and materials in the room child-friendly and safe for him to do this without harm).

During my childcare interview, I learned I would be an in-ratio support worker for an autistic child in a school daycare. I researched autism and read about it before I started work, but

most of what I did I learned on the job through building solid relationships with the children I supported. According to my favorite developmental scientist, attachment is a foundational prerequisite to bringing a child to her or his full potential (Neufeld, 2012). Why is attachment so important? Children need to attach deeply to the adults responsible for them “to find the nurturance required to support true growth and maturation. They need to do this to reverse crippling shyness and neutralize instinctive counter-will. They need to do this to reduce the separation they face. Like plants, children can never be too attached... The answer to development is always more attachment, not less” (Ibid, p. 16-17). From a developmental perspective, full human potential is about children becoming “viable as separate beings, capable of adapting to circumstances they cannot change, and considerate of others without losing themselves. [It] is the essence of developmental well-being” (Ibid, p. 3). In other words, “we must have the hearts of our children to keep their hearts soft. And they must have soft hearts to find their rest and their play” (Ibid, p. 21).

\*\*\*\*\*

### **The Problem with “Inclusion”**

“For the master’s house will never dismantle the master’s house. They may allow us temporarily to beat him at his own game, but they will never enable us to bring about genuine change.”

(Audre Lorde, 1979)

Different power dynamics are always at play in social interactions, arrangements, and institutions. Michel Foucault’s definition of power because it aligns with and complements the feminist definition of agency as self-definition and self-direction. Power is defined as “something which circulates, or as something which only functions in the form of a chain... power is employed and exercised through a netlike organization. . . Individuals are the vehicles

of power, not its points of application” (Foucault, 1980, p. 98). I used to think about power in binary terms— as something one has or does not have. For example, I thought people who are oppressed and live on the margins of society have no power because their oppressors have the power. But that is not true.

This conception of power is brilliantly articulated in Solange Knowles’ studio album, “A Seat at the Table.” She argues and shows how black Americans (like other marginalized groups) have always had tables and seats at the table—with the table is a symbol of power— even when they are oppressed. Solange’s use of the concept of a table illustrates issues of access or lack of to a given table. It denotes issues of control and ownership of power, capital, and decision-making. People have power and agency. A friend may invite me to have dinner at their table, while another, invites me to build and set up a table with them. I may decide to include someone at my table at home by inviting them to join me for dinner, lunch, or another event. The vital difference is that one invites me to sit at what they have set up, while the other invites me to co-set up and build the table from the ground up together. A friend’s presence at my table may give them access to my home and whatever food I prepare, but it does not give them the power to dictate how to run my household or set up my table and who else gets access. Therefore, there is no real inclusion without co-created with the marginalized using tools for liberation and social transformation.

Inclusion can become tokenistic, especially when we only point to representation and count the diversity of the people at established/set tables who may have no say in how decisions are made to establish and run the table. Brené Brown’s work on vulnerability, shame, and belonging reveals the dangers of integration (fitting into existing structures) and exclusion. Reading and watching some of Brown’s presentations during my disability studies has led me to believe that “true inclusion” in any given space, whether a classroom, a work office, or

boardroom, feels like belonging. In the Gifts of Imperfection, Brown defines belonging in the following way:

Belonging is the innate human desire to be part of something larger than us. Because this yearning is so primal, we often acquire it by fitting in and seeking approval, which are only hollow substitutes for belonging, but often barriers to it. Because true belonging only happens when we present our authentic, imperfect selves to the world, our sense of belonging can never be greater than our level of self-acceptance. (Brown, 2010, p.37)

Inclusion that engenders a sense of belonging involves self-acceptance and co-creation. For example, one might build a table from the ground up with others, including the type of table and the materials used to build and sustain it. A seat at the table symbolizes belonging.

### **Interlude: Navigating the Neutral Zone**

Brené Brown's definition of belonging felt like a lifeline as I worked through graduate studies and reflected on my narrative and career through a disability studies lens. As I deliberated on inclusion in all the spaces I have worked, I often felt alone and alienated. In the moments of study, I did not feel like I was making any progress, even as I sometimes felt elated as a concept began to make sense to me uniquely (for example, when I connected belonging and inclusion). I now know I had to lean into the discomfort and tread the constant waves of uncertainty and vulnerability that autoethnography requires to get to the heart of the matter. This was hard because avoiding discomfort through procrastination and distractions was easier. However, I can also argue that procrastination was necessary for my sanity. It was my body's way of taking a breather. I needed to unwillingly step away from the work for what I was reading and writing to marinate properly. Unconsciously, I wondered as I procrastinated— how can I (or anyone) be inclusive (belong anywhere or to ourselves) if we cannot present our authentic and imperfect

selves? If inclusion involves power, control, and ownership, who has the power to include or exclude? Who decides who to include and who to exclude? I do not want to fit in. I want to belong— that is what real inclusion means to me.

\*\*\*\*\*

### **Inclusive Communities of Belonging**

Belonging emerged in my data as a core theme and highest value. True inclusion, happens in a community when we remove any need for people to change who they are to fit in or be acceptable members of society. It occurs naturally when people feel safe to be authentic without reprimand (for example, prejudice or discriminatory attitudes). Being ourselves can be scary because of our innate desire for love and belonging. But, as Brown expands in “Braving the Wilderness,” individuals carry belonging in their hearts, and they need to accept the responsibility or have the courage to carry it to show up fully or authentically in community with others.

Being ourselves means sometimes having the courage to stand alone, totally alone... it [belonging] is not something we achieve or accomplish with others; it's something we carry in our heart. Once we belong thoroughly to ourselves and believe thoroughly in ourselves, true belonging is ours. Belonging to ourselves means being called to stand alone— to brave the wilderness of uncertainty, vulnerability, and criticism. (Brown, 2017, p. 32)

So, belonging comes with both personal responsibility (individual agency) or “courage to stand alone” and social responsibility (collective agency). Accordingly, as the oppressed become aware of the causes of oppression through critical dialogue, they also actively participate in changing their conditions—as opposed to passive acceptance (Freire, 1993).

The disability rights movement identifies the various ways society disables people (not impairments in the body) and reveals how to transform the world into one where persons with impairments belong, first to themselves, then through collaboration and mutual respect in community with others (power-sharing). Therefore, in my work, I emphasize creating education, home, and work environments where people, especially girls and women with disabilities, not only feel included but experience a deep sense of belonging.

### **Interlude: “A Seat at the Table”**

I sat in the Elizabeth Dafoe computer lab, reading academic articles for my research. I was reading an article on the feminist definition of agency when ‘F.U.B.U.,’ a song by American singer-songwriter Solange Knowles, repeatedly went off in my head. In this black empowerment anthem, Solange sings, “Made this song to make it all y’all’s turn/ For us, this... (song) is for us... Some shit you can’t touch.” This line struck a chord and played in my head repeatedly. It brought back some fond memories. I listened religiously to the entire album, Solange’s third studio album, when Saint Records and Columbia Records first released it on September 30, 2016. In 2016, I was still doing my undergraduate degree and working to understand myself and my place as a black African young woman. Solange’s emotional openness and vulnerability as she tackles the painful realities of black people in white-supremacist-capitalist-patriarchy America—such as racism, police brutality, and the legacy of the horrors of the enslavement of African Americans—felt like a balm of healing, comfort, and empowerment.

I pulled out my iPhone and re-listened to the entire album as I read academic articles. I reflected on my collaborative work with organizations of persons with disabilities, particularly blind women. It made me think about inclusion in the album's context. I thought about power and black women’s agency. The album’s title, “A Seat at the Table,” is a well-known phrase that

conjures up images of people's access to power and decision-making in different arenas, including in public spaces (workplaces, government, communities) and private spaces (homes, at the kitchen, for instance). I looked up Solange's interviews about the album and enjoyed learning her reasoning for making the album. About the song 'F.U.B.U.," she explains,

I named it 'F.U.B.U.' because I wanted to empower, and I looked to people who have done that in their own ways. I thought of F.U.B.U., the brand, meaning 'For Us By Us', and what kind of power it had and how normalized it became to wear that kind of symbolism every day. I remember reading stories on the product placement, and seeing LL Cool J wearing a F.U.B.U hat in a national GAP advertisement. F.U.B.U. exhibited Blackness in any space, on a huge global level, and that is what I wanted to do with the song.

Throughout the album, Solange brings her listeners through black rage, trauma, reflection, despair, empowerment, and joy. In the case of the song F.U.B.U and, ultimately, the entire album, she centers the black American experience and invites others to partake but on her terms. F.U.B.U. is specifically for people of the African Diaspora, and others are excluded from partaking in it through the use of words that only black people can sing out loud. As Solange states in a 2016 interview with NPR, being included on a table means that someone owns the table and is granting you access:

We've [black people of the African Diaspora] always had a seat at the table... I think one of the seats at the table is also saying that, you know, I'm inviting you to have a seat at my table. And it's an honor to be able to have a seat at our table and for us to open up in this way and for us to feel safe enough to have these conversations and share them with you.

\*\*\*\*\*

### **Inclusive Education**

In education circles, inclusion is often used interchangeably with integration, even though both words mean different things. While the earliest use of the noun integration is also in the early 1600s, the Oxford Learner's Dictionary defines integration as [countable] act or process of mixing people who have previously been separated so that they work or fit together. In education, integration is the placement of children with disabilities in existing regular or mainstream school systems without adjusting the school environment to accommodate them (Ibid). Children with disabilities are expected to adjust to and adapt to the mainstream classroom culture and its standardized requirements to 'fit in' (United Nations, 2016, p. 4; Cologon, 2014; Ainscow, 2002). Additionally, an integrated system employs a segregation system for part of the day to teach children with disabilities in "special" or separate education units. Segregation is used to "respond to particular or various impairments, in isolation from students without disabilities" (United Nations, 2016, p. 4).

The idea of making education more inclusive and equitable is relatively new. It formally took shape at the 1994 World Conference on Special Needs Education in Salamanca, Spain. This conference brought together more than three hundred participants from ninety-two governments and twenty-five international organizations to discuss how to enable schools to serve all children, particularly children with disabilities and special education needs (Ainscow, 2020; UNESCO, 1994). This conference marked a paradigm shift in education, as shown in the conclusion of Salamanca Statement:

Regular schools with [an] inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society

and achieving education for all; moreover, they provide to the majority of children and improve efficiency and ultimately the cost-effectiveness of the entire education system (UNESCO 1994, p. ix)

The newly defined inclusive education system aimed to develop schools to accommodate all students' differing needs and remove barriers limiting the participation and achievement of diverse learners. Within this framework, education systems are expected to operate within the view that all learners have diverse needs, abilities, and characteristics that must be respected (UNESCO, 2009). Before the Salamanca Statement, the focus was on integrating or “fitting” learners with disability and other vulnerable groups into existing arrangements. In other words, the focus was on individuals with impairment and how they can be fixed to integrate into the existing education infrastructure. Integration has no room for belonging, as learners must be different instead of being themselves to fit in. The content of the term has progressed over the years.

In 2005, UNESCO passed Guidelines for Inclusion, which introduced the idea of inclusion to provide quality education for all. However, there still needs to be more consensus about what inclusive education means, which is a barrier to its incorporation into the education sector. One of the ten recommendations in the 2020 Global Monitoring Report is to “widen the understanding of inclusive education: It should include all learners, regardless of identity, background or ability” (Antoninis et al., 2020). In addition to the definition provided earlier, for education to reach every last child, including children with disabilities, it needs to be defined and implemented through the social model of disability as elaborated in Article 24 of UNCRPD (2006). This means that a ‘one-size-fits-all’ approach does not work, especially in settings where the needs of persons with disabilities do not inform the design of the learning environment (Ibid).

Inclusive education requires continually assessing and understanding all students' strengths and interests and adapting teaching processes and procedures to accommodate their learning preferences and needs (Booth & Ainscow, 2005; Cologon, 2014). Ainscow (2020) takes this definition of inclusive education a step further and argues that inclusive education is a continuous process that involves four grounding elements. First, the process requires identifying the best ways to cater to diverse learners in an ongoing and continuous process. Secondly, identify and remove barriers to learners' full and effective participation in education. Thirdly, all students' presence, participation, and achievement, including learners with disabilities, must be upheld. Last but not least, provide additional care and attention to groups of learners at risk of marginalization, exclusion, and underachievement, such as children with disabilities, girls, and refugees (Ibid).

Ainscow's definition of inclusive education and its four grounding elements align with the definition by the United Nations Educational, Scientific, and Cultural Organization (UNESCO, 2009). Both call for a commitment to eliminate discrimination in the learning environment to honor the diversity and dignity of all children. It requires using an intersectional approach to ensure that all students, with their diverse social identities or markers of difference, are supported. For example, a Rwandan girl with a disability living in a poor family in a rural community of ethnic minorities. These social markers (girl, poor, disabled, ethnic minority) are all sources of disadvantage.

### **Interlude: A Deaf Child in a Rwandan Public Classroom**

He sat in the front row and quietly followed the teacher's instructions. For an outsider, Butera looked like all the other grade three students. There was nothing too distinct about him. I had seen him playing football with other boys earlier in the day. He was at one of the sixty

Inclusive Model Schools across the country, which were receiving extra financial and technical support from UNICEF through Humanity and Inclusion to equip schools to accommodate children with different disabilities in their neighborhoods better. Most teachers at the school had received some form of basic training on SNIE, and a few more were receiving training led by their Inclusive Focal Teacher (IFT). The school also received some funds to add an accessible toilet and make minor adjustments to the infrastructure for accessibility. The headteacher told me they were more inclusive now and selected Butera's class as an example of incorporating SNIE training into the classroom. The classroom, packed with over forty students, was adorned with up to two charts with math problems on the walls. The teacher kept the classroom engaged through interactive mathematics problem-solving on the chalkboard. She also had mathematics instruction aids for counting, including locally made wood blocks, beans, and small bins.

Whenever the teacher asked for volunteers to solve a math problem, most of her students raised their hands in the air while chanting loudly and repeatedly in unison, "Me, teacher! Me, teacher! Me, teacher!" She called on Butera about twice in a ten-minute framework, but he failed to solve the simplest math problem. There was frustration and a clear disconnect in their communication as the teacher tried to help her student complete a simple division problem. She wrote numbers and drew signs and representations on the chalkboard, such as  $9 \div 3 = \underline{\quad}$  (the students were asked to fill in the blank). She drew mangos to illustrate the problem. But Butera looked blank and failed to tally the correct response. He wrote 5, then 6, from the teacher's further prompting. The teacher tried to explain with a few words and then wordlessly, but all her communication and the few signs she used failed to register with Butera. It was clear that he had no idea what was happening with the equations— even though the head teacher told me he came

to school regularly with all the other children. He had repeated third grade, and by the looks of it, he was likely going to repeat since he was behind compared to his peers.

Meanwhile, the students grew restless in the classroom and continued chanting, “Me teacher! Me teacher!” with Butera’s every failed attempt. Butera worked quietly and calmly, clearly wanting to be part of the commotion in the classroom, even though he did not understand the lesson. He had put his hand up because he saw other students around him doing that.

\*\*\*\*\*

### **Overview of Inclusive Education in Rwanda**

Over the past decade, Rwanda’s education sector has made some progress in promoting inclusivity and equity. The Government has established a strong legal framework consisting of laws, policies, and commitment to safeguard the rights of persons with disabilities. Moreover, Rwanda has ratified various international conventions and protocols, including the Convention on the Rights of Persons with Disabilities (ratified in 2008) and the Protocol to the African Charter on Human Rights on the Rights of Persons with Disabilities (signed in 2019). Rwanda’s education system has four levels: early childhood, primary, secondary, and tertiary. At the national level, Rwanda’s commitment to the education of persons with disabilities is particularly reflected in the Special Needs and Inclusive Education policy and its Strategic Implementation Plan (revised in 2018), the National Policy on Persons with Disabilities (2021), the Education Sector Strategic Plan (ESSP 2018/19 – 2023/2024) and the 2016 Competence-Based Curriculum.

Under the Revised Special Needs and Inclusive Education Policy 2019, provisions must be made for the inclusion and optimum participation of all learners with special educational needs within Rwanda's full range of educational services:

...addressing all learners' educational needs in a mainstream education setting. It is based on the principle that all learners are different, and can learn and develop differently, and therefore, the education system is expected to flexibly be adapted to fit every learner's (child's) needs. (Ministry of Education 2019, p.6)

To support the implementation of the SNIE policy, the Special Needs and Inclusive Education (SNIE) unit was established in 2020 by the Rwanda Basic Education Board, the Ministry of Education branch in charge of implementing basic education in Rwanda (World Bank, 2023). Furthermore, a massive construction initiative, including some accessible features, was carried out during COVID-19 school closures to increase classrooms and reduce overcrowding (Ibid).

Yet, like most low-income countries, Rwanda's general budget and financial basket for education is small and tight. The Government of Rwanda allocated FRW 786.9 billion for the education sector for the 2023/24 fiscal year, representing a 17 percent increase compared to the previous FY 2022/23 budget (the sector received 675.0 billion) and 15 percent of the national budget (Ministry of Education, 2023). Over the past five years, an analysis of budget allocations for education has shown a positive trend and government commitment to strengthen human capital development through education. Still, the budget needs to meet education needs and the Education Sector Strategic Plan (ESSP) 2018-2024. Amidst these budget gaps and structural inequalities, non-governmental organizations (NGOs) play a significant role in funding primary education (UNICEF, 2022).

Furthermore, a significant disparity remains between policy intentions and on-the-ground outcomes (Njelesani, Siegel, & Ullrich, 2018). Barriers to education of children with disabilities are still many and can be categorized under institutional, communication, attitudinal, and physical barriers (Mutezigaju, 2019; Bots, 2015; Mattingly & Suubi, 2015). Persistent

challenges to quality education of children with disabilities are due to resource inequity, including a lack of reliable data on in-and-out-of-school children with disabilities and poor supply-side issues—training on inclusive education pedagogy, SNIE teachers, accessible learning materials and physical infrastructure, disability-specific education specialists—to meet demand for equitable and inclusive education for all. Households with persons with disabilities are disproportionately affected by poverty and unemployment, with approximately forty-one percent of adults with disabilities having not completed formal education (NISR, 2012).

Most of the schools that I visited during my fieldwork in Rwanda over four years, including those that were categorized as “Inclusive Model Schools” because they received additional support from UNICEF through Humanity and Inclusion (HI), were more integrated than inclusive—based on the definitions of both terms. Now and then, I would find one deaf student or a blind learner here and there (among other disabilities) enrolled in a mainstream school. I met Butera on one of my monitoring rounds of teacher training in special needs and inclusive education (SNIE) in 2022.

### **Interlude: Reading “Pedagogy of the Oppressed”**

When I first read “Pedagogy of the oppressed” as an undergraduate student at the University of Manitoba in Canada, I identified with the oppressed group as a black African woman living in what bell hooks calls an “imperialist white supremacist capitalist patriarchy” (1984). However, Rwanda's power dynamic is different, especially in rural areas. As a development worker, it occurred to me that I could be the oppressor. This reflection was disturbing and uncomfortable. Whenever my colleagues and I visit a community, most people look at us like we have the answers, the solutions. The parents told us about their children with

disabilities and why they could not read or even go to school. One single mother told me about how her four-year-old daughter became deaf:

She started complaining about her ears. She said they were hurting and ringing. She was inconsolable for a while. We live far from the nearest hospital, and I did not have enough money to take a bike. But she was in so much pain, so I found a relative to borrow enough for a ticket. When we arrived, the doctor told us it was an ear infection and would probably clear up after a while. He also gave us some medicine and recommended seeing a specialist in Kigali if the pain persisted. By the time I raised enough money to go to Kigali, it was already too late. She is now completely deaf. She dropped out of school because it was too much work to understand anyone, and people mocked us. Some say that my in-laws are behind it for my husband's death— you know that they are practicing witchcraft against me and my child. (Personal field journal, 2021)

Stories like this were common. Many parents said they failed to get treatment or sufficient medical attention for their children when it was needed because it was too expensive—even though registered Rwandan citizens get free medical care as per income level— because it often required traveling to Kigali City, the capital city, for specialist services. Public transport costs range anywhere from six thousand (a two-way ticket for a parent and child) to eight thousand Rwandan francs, depending on the district. A few “lucky” children get specialist services such as physiotherapy through charity organizations or from random well-to-do strangers who hear their stories and take it upon themselves to help. I also met a couple of children who were unregistered because their parents were undocumented immigrants. One of the children was deaf, extremely malnourished, and had never been in school. He lived with an

extended relative (as his mother was imprisoned). They were unsure whether he was deaf or “refused to speak.”

We got various cases of abuse from youth with disabilities. Some children with disabilities were hidden in their homes (this was more common in Kigali). In contrast, others, particularly those with multiple disabilities, were tied to trees like animals by their caregivers. We encouraged youth volunteers and literacy champions to report these cases directly to village leaders and representatives of people with disabilities in their sectors and regularly follow up with the families.

Lorde and Freire have written extensively on why raising critical consciousness through education is the only way to empower the oppressed to fight for their liberation. In the words of Freire (1993):

...for the oppressed to be able to wage the struggle for their liberation, they must perceive the reality of oppression not as a closed world from which there is no exit, but as a limiting situation which they can transform. This perspective is a necessary but not sufficient condition for liberation; it must become the motivating force for liberation action. (p. 49)

Through self-reflection and dialogue in community with others, oppressed groups can become aware of a limiting situation, accept their humanity, and gain the motivation to transform their lives individually and collectively. Coming to critical consciousness is not an easy process but is made possible through dialogical action, which includes 1) dialogue about one’s limiting situation and 2) action for social transformation.

### Chapter Three

#### **Inclusive Education Practices in Rwanda: Progress and Challenges**

“When they enter, we all enter.” ~ Kimberle Crenshaw (1989, p. 167)

Inclusive education, built on principles of equity and anti-oppression, is a cornerstone of an equitable and fair society for all. As elaborated in chapters one and two, building an equitable society requires addressing systemic barriers that prevent children, including those with disabilities, from access to quality education. In this chapter, I examine the approaches and practices used to implement inclusive education at the local and national levels in Rwanda and their impact on the learning of children with disabilities. I begin by sharing a story of a family of a child with a disability I encountered in a rural village in Rwanda early on in my career in inclusive education that caused a shift in my professional approach and practice. I share memorable stories and observations from my field travels across Rwanda to shed light on some of the complexities, realities, and impact of implementing an inclusive education policy and practices in Rwanda at the national and local levels. My visits were for various activities, including monitoring the implementation of different inclusive school-based or community-based education project activities, assessments, and research initiatives.

I visited over sixty public primary education schools during my four-year employment history in Rwanda between 2020 and 2023. I interacted with over a hundred parents and caregivers in twenty-nine of the thirty districts in the country (except for Gakenke District). I start by documenting my observations of disability inclusion approaches and practices from the village level. Followed by disability inclusion approaches and practices at the national level. My observations demonstrate some progress in addressing barriers faced by children with disabilities

and their families. However, the effectiveness in improving learning outcomes depends on sustained resource equity, including teacher training, building accessible infrastructure, strong community engagement and partnerships between different stakeholders, and evidence-based advocacy to ensure equitable and transformative inclusive education.

### **Interlude: Umuhoza's Right to Education**

I was traveling across Rwanda to monitor the implementation of pilot disability inclusive approaches to community-based literacy promotion. It was June 2020, and we had just come out of the first wave of total lockdown for coronavirus disease (COVID-19), which lasted over two and a half months. We wore face masks, carried hand sanitizers, and were required to maintain a physical distance of at least one meter from each other to avoid catching and spreading COVID-19. This was my first role working for an international non-governmental organization, Save the Children, and I was confident I would change the world for the better for children. Eglantyne Jebb, the founder of Save the Children, inspired me, and my life's work was fueled by the belief and Jebb's words: "Humanity owes to the child the best it has to give."

The project worked with youth volunteers with disabilities to map children with disabilities in primary grades one to three in their community and train their parents on practical ways to support their children with disabilities to read and learn at home (in addition to formal education). The youth volunteers were recruited in partnership with district and local village leaders and under the leadership of a local organization of youth with disabilities through their social media pages, primarily WhatsApp. Most of the youth were already serving in their local communities as representatives of persons with disabilities, so they responded to the call eagerly. Partnering with local leaders early on in the recruitment process was key to the success of the project as they remained engaged and responsive throughout the pilot. In all five districts of the

pilot local leaders not only participated and provided input during training, but they provided training venues and other resources where available (for example, some of them became advocates and provided referrals for caregivers who needed extra assistance as they learned about disability and received requests from youth volunteers with disabilities). It would be interesting to see whether this momentum is sustained after the end of the project.

On one of my monitoring rounds to a remote rural village in the south of Rwanda, I met Umuhoza, an eleven-year-old girl with a physical disability, her mother, and her twelve-year-old brother. We left our Jeep on the main road and descended a steep, narrow, muddy path to a two-room mud house with a broken wooden door and old iron sheets. A male youth volunteer with a physical disability, Jean, called out to Umuhoza's mother, Ineza, and we waited for over a minute before she came rushing out in a worn-out floral kitenge wrapper (a piece of clothing commonly worn by many women in Rwanda, especially those in the village) and a white blouse that had turned brown-ish from wear. She invited us to enter a dark living room with one piece of furniture and a bench. Ineza called Umuhoza, who came in slowly and with a bit of a limp.

Umuhoza was bright-eyed, attentive, and wore a brown dress. Ineza told us that she was an intelligent child, but she was not enrolled in school. I told her that Umuhoza had the right to attend school like all other children. I said education was a human right and asked her if she knew she could get in trouble with the local authorities for denying Umuhoza that right. Upon seeing her response and the look in her eyes, I immediately regretted employing the human rights armor against her. She was on the verge of tears as she explained her living situation as a poor single mother of two children below thirteen, including one with a disability. She told us that she had no family and only managed to feed her children by farming for someone else. And even then, they often survived on just a meal a day. Their house belonged to her employer. She said

she had to feed her children or take Umuhoza to school. The nearest school was a fifteen-minute walk from their home and almost an hour for Umuhoza as she had to walk slowly due to pain and take frequent breaks.

Umuhoza had no access to school. Walking to school every day was not sustainable due to physical pain. Ineza could not carry her (as some parents in the community do) because she had to do farming work very early in the morning, but Umuhoza was too heavy to lift. Umuhoza's older brother (by a year) also often missed school to look after his sister because their mother was working. They were completely isolated and without a family network, as Ineza had left her hometown in the west of Rwanda in search of a better life for her children (I suspect that Ineza is a survivor of the 1994 Genocide against the Tutsi). Ineza reported that they were often victims of violent crimes, particularly robbery. Even the books we gave them during a back-to-school campaign in 2020 were stolen. They lived in insecurity and dire socioeconomic conditions, barely making ends meet. Yet there I was, a fresh Western educated Bachelor of Arts graduate, with all my naivete and privileged background, accusing her of a 'human rights violation.' What kind of people do that? My tone, even though I meant well (my words came from a foundational drive for every child to access quality education and live in a nurturing and safe environment conducive to their well-being and growth), haunts me to this day. This encounter with Umuhoza, her mother, and her brother marks a shift in my inclusive education approach and practice in my professional work.

\*\*\*\*\*

### **Implementation of Inclusive Education in Rwanda: Approaches and Practices**

The Ministry of Education and development partners have employed various strategies to address gaps in the education of children with disabilities, including implementing disability

awareness community programs, piloting Universal Design for Learning, training teachers on SNIE, providing assistive technology or EdTech solutions for inclusion, building and equipping resource rooms and teacher aides (Bots, 2015; Mutezigaju, 2019; USAID, 2020; Save the Children, 2020; 2021; Chemonics, 2021; World Bank, 2021, 2023). Research or evaluations are lacking on the extent to which any of these strategies effectively address the need for quality inclusive education and improved learning outcomes of children with disabilities in the Rwandan public education system. In this chapter, I share my observations on the inclusion of children with disabilities in literacy activities. I met Umuhoza and hundreds more families of children with disabilities while working on a community-based project to improve early literacy outcomes of children in primary grades one to three in villages in all thirty districts of Rwanda. The living conditions of Umuhoza's family mirror that of many families of children with disabilities in Rwanda, particularly the majority of Rwanda's total population who live in rural areas and subsist on small-scale farming.

### **Part 1: Observations About Inclusive Education at the Local/Village Level**

In 2018, Save the Children conducted a midline evaluation of their USAID-funded early-grade community literacy promotion project and found that children with disabilities were not equally benefitting from the initiative because they were not participating in the activities, including reading clubs (Save the Children, 2018). Shortly after this study, USAID awarded Save the Children a two-year costed extension, with a clause that at least five percent of the total budget goes towards disability inclusion. I was recruited as the disability inclusion lead and worked with an organization of persons with disability to pilot community-based inclusive approaches to literacy promotion. The pilot employed youth with disabilities as positive role models in their communities, leading efforts to promote literacy in their villages and homes of

children with disabilities. Youth with disabilities and other community literacy volunteers were trained on how to map children with disabilities in their villages, conduct various community awareness-raising to improve early literacy outcomes of children with disabilities, train parents of children with disabilities on how to support their children's reading and learning at home and conduct regular home visits to help families of children with disabilities at home.

Youth volunteers also worked with other volunteers and community service providers (including literacy champions, community health workers, Ishuti z'Umuryango or friends of the family) to increase the participation of children with disabilities in various community activities, such as reading clubs. Literacy champions ran weekly reading clubs for children in primary grades one to three. Through joint work between youth with disabilities and literacy champions, the participation of children with disabilities in weekly reading clubs increased. By the end of the project, over three thousand families of children with disabilities were reached, and three thousand reading clubs with children's storybooks were established in villages nationwide. Below are some general observations and lessons learned from this community-based pilot project.

***Interlude: All Children Deserve Accessible Books to Read***

It was a Sunday afternoon. We all sat in the large living room of one of my dad's friends. I was about twelve years old. My brother sat on the edge of the couch to my right while the son and daughter of the couple we were visiting sat across from us. The TV was on, and their eyes were glued to it. At the same time, our parents were chatting and laughing as they sipped their cup of tea or beer. The men drank beer while the women drank African tea— a local blend of ginger, black tea, milk, and sugar— with samosas, meatballs, and chapati.

I sat on a black leather couch with a medium-sized book in hand, my right arm resting on

the arm of the sofa with my legs folded and tucked under my light pink dress. Small tears and holes were on the leather couch from wear and distress. Usually, they would bug me, and I would start pulling on any threads that stuck out in a miserable attempt to fix them and hide the ugly bits. Sometimes, I would try to understand why the owners did not fix it. Did they not see how small tears like this distract from the beauty of the rest of the couch? Were they just careless with all their possessions? Why did they choose leather and not something plusher? I would often wonder. But not today. I was perfectly fine sitting on the couch, lost in Sweet Valley High, California, with my favorite identical twins, Jessica and Elizabeth Wakefield.

With a novel and an exciting storyline, I could sleep through any storm—with my eyes open. Random family visits usually made me anxious, and books made me feel like I belonged everywhere and nowhere— I just was. Books bring comfort, hope, and a beautiful escape from everyday life (and we all need that sometimes, if not most times). They transport children to far-off places and allow them to imagine living in a different reality where they can be anyone and do anything. One of my favorite childhood memories is that I spent much of it reading the Twilight series day and night. Nothing can top the minutes and hours I spend lost in a good written story, fiction or otherwise.

\*\*\*\*\*

### ***Intersectionality: Most Inequality Starts in Childhood***

Discrimination and prejudice based on gender, age, disability, and other culturally marginalized identities is real. It happens in our homes, offices, boardrooms, and other social spaces.

**Interlude: Excerpt from a Journal Entry on Discrimination.** They, particularly men and non-disabled people, will tell you not to use the word discrimination in meetings and

workshops (I was told this many times). They will tell you that the word “discrimination” is too harsh, inaccurate, and wrong. You will begin to question yourself as you speak about it. You will think, “Maybe it’s my tone. It’s too harsh. It is too serious. I should tone it down.” You must take a beat in these instances. Pause for as long as you need to do some breathwork (practice what you learned in the racialized trauma group at the university). Then, go back to work.

Discrimination is very real, and it affects girls, women, and children with disabilities every day—sometimes, the consequences lead to death. Many girls across Rwanda live in situations like Umuhuza: disabled, out of school, single-female-headed households, and poor. Pay close attention to what people tell you in meetings and workshops. If something, like the stories below, stands out to you, note it and reflect on it later.

\*\*\*\*\*

During a discussion session on intersectionality or the inclusion spectrum (how some children face multiple forms of disadvantage), a male participant shared the following about the cultural reality of inequality of education for girls:

I know that boys and girls do not get treated equally. If you want to understand this, look at it this way. Two siblings, a girl and a boy, do well on primary six national exams. The boy can continue his studies while the girl is forced to stay home because the family cannot afford to send both of them to school. For them, sending the boy, not the girl, is logical because the boy is seen as a better investment and is always prioritized. We see this every day. That is why I would put girls and women on the lower rank of the spectrum of inclusion. (Save the Children, 2020, Inclusion Refresher Training annex)

For children with disabilities, disability intersects with various socioeconomic variables, such as gender and class, to create adverse life outcomes for them. Caregivers reported that the children

with disability were not in school because of one of four reasons: (1) the parents did not think their children were capable of learning; (2) teachers, including head teachers, believed that the children could not learn and therefore sent them away from school or the children's behaviors were disruptive in classrooms, and they could not teach them; (3) the families lacked the resources, including assistive equipment such as wheelchairs, to send their children to school; (4) the school environment was not accessible for children with disabilities (lack of accessible toilets, walkways, furniture, very steep and hilly terrain).

The majority of the female parent beneficiaries of the pilot also reported that family members, including their husbands, abandoned them after they gave birth to a child with an impairment. As a result, many children with disabilities who benefited from this community-based activity were under the care of their mothers, grandparents, or other community members who took them under their wing after their parents abandoned them. This is because there is a common superstitious belief that women who give birth to children with disabilities are cursed and bad omen (Karangwa, 2006).

### ***Disability Awareness is Key to Eliminating Attitudinal Barriers***

The most significant barriers to education of children with disabilities are attitudinal. Negative social attitudes toward disability and gender impact the everyday life experiences of girls and boys. Girls like Umuhoza are 'triple' disadvantaged and marginalized because of (i) gender, (ii) impairment, and (iii) poverty. As seen in the story told by a participant at a community workshop, children with impairments are further marginalized in their communities, including at school and home, due to stigma:

Attitudes are a major barrier that hinders children with disabilities from participating in

community activities. Some parents are ashamed of their children with disabilities, and they do not treat them the same as their siblings. There is a family with four children, including one with a disability. You never see this child with a disability participating in family activities or community gatherings. This child is mostly hidden and left out of everything. (Save the Children, 2020, [Inclusion Refresher Training annex](#))

Attitudinal barriers and lack of knowledge about proper care for children with disabilities can have fatal consequences. A youth volunteer shared a tragic story from one of the caregivers, a mother of Ineza, a child with disabilities, participating in the community workshops. Ineza's story shows the tragic consequences of ignorance about how to properly care for children with disabilities, particularly those with multiple disabilities. It also shows that raising awareness of disability among parents and caregivers makes a positive impact within a few months.

A mother of a child with disabilities in the inclusion workshops shared this tragic story, and it tells of the lived experiences of children with disabilities. One day, the parents went out to cultivate the land, taking the goats with them. As usual, their child with multiple disabilities was chained to a stake where the goats stay. The child would stay there alone until everyone came back home. Then, one day, heavy rains came and found the child outside—alone, chained to a stake. It rained for hours and hours. When the parents came back home, they found the child was almost unconscious and rushed her to the nearest hospital. But the child did not make it. She died.

These parents did not mean ill by treating their child like this. They were employing the only strategy they knew how to.

I am working closely with families like this so they can learn how to better care for their

children with disabilities. The mother who shared this tragic story with me has another child with disabilities, and she has found the parents' workshops helpful. Her relationship with her child has changed tremendously; she is interested in her child and sees her unique abilities. She doesn't want to lose another child. We need people's attitudes towards people with disabilities to change." (Save the Children, 2020, Inclusion Refresher Training annex)

### ***Poverty Causes Disability, and Disability Causes Poverty***

Design programs and activities with the understanding that many children with disabilities are out of school, poor, and often live in single-female-headed households. Murezi's story below illustrates impairment can be caused or worsen over time due to poverty and limited knowledge.

"There is a child in my sector with a physical impairment that has worsened over time because of lack of knowledge and negligence. His parents did not know that treatment was possible, and now his legs are almost conjoined. There are a lot of people in the community who do not know what is possible for children with disabilities. They think it is just bad luck and witchcraft, so they don't know nor have the resources to seek medical care." (Save the Children, 2020, Inclusion Refresher Training annex)

Persons with disabilities, such as Rosangela Berman-Bieler (2013), illustrate the great cost that comes with expenses for medical treatment and rehabilitation, worsening the living conditions (putting families of children with impairment into the poverty cycle) and worsening their health chances and well-being. Children with certain impairments who do not get medical treatment die prematurely or, like Murezi, their impairment worsens over time, thereby limiting their chances

at education and employment and increasing their chances of exclusion.

In a press release, UNICEF (October 14, 2024) reported that “nearly two million severely malnourished children are at risk of death due to funding shortages for therapeutic food.” The majority of the countries affected are in Sub-Saharan Africa, including Cameroon, Chad, South Sudan, Kenya, the Democratic Republic of Congo, Uganda, Nigeria, Niger, and Mali. In Mali alone, over 300,000 children under the age of five are expected to suffer from severe wasting in 2024 (UNICEF, 2024). I also saw this lived reality in many communities I visited in Rwanda. According to the latest Rwanda Demographic and Health Survey, 2019-2020, thirty-eight percent (661,200) of children under five years are chronically malnourished (stunted or have low height-for-age), and thirty-seven percent (643,800) are anemic (NISR et al., 2021).

Risk factors for poor nutrition, such as poverty, maternal ill health, and depression, are common in Africa (Kerac et al., 2014). Therefore, early childhood development and education programs must use a whole-child approach and work more closely together, including nutrition and disability programs. Various studies show that maternal nutrition can increase the risk of perinatal problems, including birth asphyxia, which is a significant cause of neurologic damage and cerebral palsy, as well as adolescent and adult issues, including attention deficit disorder, conduct problems, and low socioeconomic status (Kerac et al., 2014; Gladstone, 2010; Penido et al., 2012; Galler et al., 2012; Galler et al., 2012, Lutter and Lutter, 2012). Other disabilities that can be caused by malnutrition include blindness from lack of vitamin A, intractable epilepsy from poor intake of vitamin B6, and cognitive impairment from inadequate iodine and iron (Kerac et al., 2014). Studies also show that poor health services or lack of access to timely treatment cause infection (meningitis and cerebral malaria), perinatal asphyxia, and jaundice

(Gladstone, 2010). The prevalence of childhood neurologic impairment alone is estimated at nineteen to sixty-one per 1000 children (Kerac et al., 2014).

Youth volunteers responded to all of the above barriers faced by children with disabilities and their families by (1) sharing their own success stories to combat negative beliefs about the capability of persons with disabilities; (2) encouraging caregivers to visit and work with school administrators to enroll and improve the participation of children with disabilities in school (for example they made individualized education plans, and some parents volunteered to support teachers as education assistants, carry out Umuganda, a monthly community work to make school terrain such as roads to schools accessible); (3) mobilize through NCPD and the district office to get specialized equipment such as wheelchairs or donors to send children with disabilities to special schools and enroll them into different social protection mechanisms; (4) conducted home visits to teach parents how to support their children's learning at home by teaching them activities of daily and using different approaches (storytelling, songs, reading storybooks to children every day).

### ***A Twin-Track Approach for Social Protection and Poverty Alleviation***

Employ a twin-track approach to address barriers to access to poverty alleviation programs for families of children with disabilities. Firstly, Rwanda has a few social protection and poverty alleviation mechanisms to support vulnerable families, such as persons with disabilities, including free health care and the "Gira Inka" (own a cow) initiative based on a single dimension of poverty: household income level. Disability is not mainstreamed in these poverty alleviation initiatives and social protection mechanisms. Caregivers reported that additional expenses associated with caring for a child with an impairment were often not

considered when determining a household's "Ubudehe category" (income category). There are currently no disability grants, child support grants, or unemployment grants. Caretaking often falls on women, who usually cannot work while taking care of a family member with a disability full-time. Also, given that the last national identification of persons with disabilities was conducted in 2012 (using an identification tool developed in the 1990s in Belgium), most children with disabilities do not have a disability card, thus limiting their access to certain social services. For example, a household that owns a piece of property is placed in a higher income bracket, regardless of whether they have a child or parent with an impairment.

Secondly, there remains a need to simplify access to social services for families of children with disabilities to navigate and get access. Caregivers of children with disabilities and youth volunteers with disabilities reported that it is not easy to navigate the system to access social systems and programs for additional assistance. The Ministry of Local Government has a structure in place to offer additional social assistance to persons and families of children with disabilities. For example, the National Council of Persons with Disabilities (NCPD) is a government agency under the Ministry of Local Governance. It was created by the constitution of June 3, 2003, as a public "forum for advocacy social mobilization on issues affecting persons with disabilities in order to build their capacity and ensure their participation in national development" (NCPD, 2024). The government funds most of its work, and its leadership structure prioritizes and employs persons with disabilities, with all its local representatives (at the village level) being persons with disabilities.

At the local level, there are representatives of persons with disabilities, two per village sector, and a District coordinator who are directly under or overseen by NCPD. There is a Disability Mainstreaming Officer (DMO) who sits in the district office and is responsible for

leading the mainstreaming of disability in government programs from the district level to the village. Some DMOs reported that they were pulled from a different department and appointed to the office without any training and understanding of disability and what kinds of additional support “people like this need.” Furthermore, most caregivers of children with disabilities did not know that there were appointed leaders with whom they could speak to advocate for their children’s needs.

Thirdly, there is no nationally standardized tools, assessment and referral system to provide necessary assistance to children with special education needs at the village, sector, or district level (World Bank, 2023). So, different tools and approaches are used to identify and reach children with disabilities. A youth with disabilities expressed the frustration that most caregivers feel at the lack of resources and accountability for people with disabilities.

It is so hard here—even when certain specialized equipment is available, we often do not get it because the people in charge do not know what to do with it. A while back, I discovered that the district had wheelchairs. Do you know that those chairs were locked in storage until they started rusting? Meanwhile, many children do not attend school because they cannot walk. Do you know how hard it is to get people to do things here? Many of us who went to school went to special schools through charity. Most families of children with disabilities are too poor to afford basic things, let alone pay tuition at special schools. I have referred some parents to NGO-led initiatives where they can get some assistance. (Personal field journal entry, 2020)

The Ministry of Education, in collaboration with UNICEF and Humanity and Inclusion, piloted a successful special education needs (SEN) and referral system in five districts (World Bank,

2023). The SEN referral and assessment has six steps, including (1) identification of children with ‘special needs’ by a teacher(s); (2) preliminary assessment by the headteacher using an early assessment checklist; (3) referral by the school to the multi-disciplinary assessment team (MDAT) which consists of district officers and medical professionals; (4) multi-disciplinary assessment and necessary intervention follow ups; (5) school placement in special schools or inclusive school according to identified needs and individual education plan; (6) case closure after completion of all five steps (M. Rose, personal communication, September 11, 2022).

The SEN referral and assessment aims to ensure schools with children suspected of SEN get timely support and referrals to appropriate services as necessary (Ibid). The multi-disciplinary team is comprised of parents or caregivers, headteacher or teacher, district director of education, special needs education coordinators (where available), district disability mainstreaming officer, district social affairs officer, psychologist, general physician (from District hospital), occupational therapist, and psychotherapist (Ibid). In their 2023 annual country report, UNICEF reported reaching seven thousand children with disabilities, including providing physical therapy to fifty children, thirty percent with health care (such as daily medication for epilepsy), and eighty percent were enrolled in school.

Furthermore, there is yet to be a national consensus on which tools to use in identifying children with disabilities, so NGOs conduct small-scale identification in select districts. When we started the pilot, it took us a lot of time to identify children with disabilities as this data was unavailable. We developed a community mapping tool using the Washington Short-Set of Questions to locate families of children with disabilities in five districts. This approach took a lot of time and resources that could have gone to something else if the district or sector office

had readily available data to target our intervention. Coordination of disability inclusion interventions is also lacking, which causes duplication of efforts by various non-governmental organizations, whose work in disability also tends to be small-scale and short-term, so it is hard to know their long-term impact on communities. Some districts get more support from various development partners each year, while others get nothing.

***Education Needs to be a Community Affair: ‘It Takes a Village to Raise a Child’***

Community-based rehabilitation (CBR) initiatives have successfully reduced barriers faced by persons with disabilities in their villages. Local civil society organizations of persons with disabilities, like the National Union of Disabilities Organizations of Rwanda (NUDOR), employ community-based rehabilitation (CBR) initiatives, including income generating activities, saving groups, and self-help groups, to lower disability poverty and increase community resources and income for persons with disability. NUDOR is an umbrella civil society organization established in 2016 by eight organizations of persons with disabilities, including AGHR, Collectif Tubakunde, NOUSPR, NPC Rwanda, Rwanda Union of the Blind, Rwanda National Union of the Deaf, and THT (NUDOR, 2024). NUDOR’s mission is to “serve as a voice of member organizations to advocate for disability rights, inclusion of all aspects of life, and their full and effective engagement in sustainable programs” (2024). While there is limited research, the CBR approach has been shown to be successful in improving the living standards of persons with disabilities and their families through increased access to community resources, including the participation of children with disabilities in neighborhood schools (Malik & Nadeem, 2022; Hodge et al.; O’Toole 1991). Key community members include i) people with disabilities, ii) families of children with disabilities, iii) government agents, iv) community workers, and v) all other community members without disabilities.

Community-based disability inclusive initiatives like the one I worked on early in my journey as a development worker in Rwanda have proven to me the need for education built on relationships involving everyone in the community, between children, their caregivers, and teachers. Work on child development and attachment theory by Gordon Neufeld (2012) and Deborah MacNamara (2016) shows that attachment to caregivers and teachers influences children's school success. Secure attachment to primary caregivers is associated with higher grades, greater emotional regulation, social competence, willingness to take on challenges, and lower levels of ADHD and delinquency compared to insecure attachment (Bergin and Bergin, 2009). Yet, caregivers and teachers do not interact enough in our schools. Most caregivers I interacted with through the project did not feel empowered to critically engage their children's teachers on education matters. They felt that education was the thing of teachers and other professional educators. For example, in a survey of thirteen schools (twelve inclusive model schools), only thirty-eight percent reported using individual education plans (IEPs), and thirty-one percent reported that they did not know what IEPs are or how to develop them. Schools where IEPs are used reported that parents were not engaged in their development.

As a result, many frustrated caregivers of children with severe disabilities, including intellectual disabilities, reported that their children were not learning or making any progress in school. These children were either made to repeat grades or were promoted from one grade to the next without a report card or formal assessment. There is often no system in place in most public schools for parents and teachers to track progress in school for children with intellectual disabilities, for example. IEP is a good method for schools and caregivers to keep track of the development of academic, social, and emotional skills in children with disabilities. Yet, in low resource and overcrowded schools, they can be difficult for teachers to develop and utilize, with

many students without additional support from a teacher's aide. Our community project showed that caregiver and teacher cooperation is strengthened with targeted community sensitization on the value and promotion of active teacher-parent partnership for child development and achievement, especially for children with disabilities or behavioral challenges.

My observations at the village level led me to agree strongly with conclusions from developmental science that children's well-being and, by extension, societies depend upon the extent to which the state supports families to raise our children, including those with disabilities.

First of all,... support[ing] families to do what they can do to allow the child's capacity for relationship to develop fully before requiring the child to be apart from family.

Secondly, it should be the mandate of the state to support the child-parent relationship, reducing the separation a child faces when apart from the family, be it in care or in school. Thirdly, it would be important to interfere with families only when children are truly at risk and with the knowledge that the added separation may indeed exacerbate the problems. The role of the state should never be to replace the family in the lives of children as attachments are family business, and growth can only be homegrown. The well-being of our children and the future of our society depends entirely upon the willingness and ability of the state to support the family to raise our children. (Neufeld, 2012, p. 22-23)

## **Part 2: Observations About Inclusive Education at the National Level**

Between 2022 and 2023, my roles were geared towards supporting the implementation of the SNIE policy at the national level. I conducted several studies, including a context assessment of the education of children with disabilities and the provision of assessment accommodations

during national exams. I led the planning and coordination of national-level events, including the launch of the Orbit Reader 20 in Rwanda (UDL and use of assistive technology in education), teacher training in disability inclusion, and the World Bank's Inclusive Education Initiative closing event. I also facilitated the change and transition of the newly established Special Needs and Inclusive Education unit in Rwanda Basic Education Board.

Ultimately, analysis of my work in various roles at the national level, shows change from traditional segregationist education framework to inclusive education for increased enrollment, equal participation, and completion of school for children with disabilities is on the other side of good transition management. Rwanda's Ministry of Education has well-articulated policies, plans for SNIE, and a new organizational structure to mainstream SNIE at REB. However, change in the life outcomes of persons with disabilities is dependent on how well this transition is managed. In the words of William Bridges, "People can implement change in a way that it does not end up hurting the organization more than helping it. The question is how?" (1991, p. 6). Accordingly, "Change is not the same as transition. Change is situational: the new site, the new boss, the new team roles, the new policy. Transition is the psychological process people go through to come to terms with the new situation. Change is external, transition is internal" (Ibid, p.3). In the next section, I reflect on the opportunities and challenges I observed in our effort to support the implementation of the SNIE policy at the national level.

### ***Institutional Framework for Inclusion: The SNIE Unit***

"The world fears a new experience more than it fears anything. Because a new experience displaces so many old experiences. . . The world doesn't fear a new idea. It can pigeonhole any idea. But it can't pigeonhole a real new experience." –D.H. Lawrence, English novelist (Bridges,

1991, p. 50)

When I was recruited and embedded in Rwanda Basic Education Board (REB), the basic education implementation agency of the Ministry of Education (MINEDUC), to provide technical assistance to the Special Needs and Inclusive Education (SNIE) unit, focusing on matters concerning the education of children with physical disabilities, I was surprised by the emotions that came with the role. The SNIE unit was established over a year before I joined REB. I came in with the understanding that I would be working under an SNIE director and alongside other specialists, including a visual impairment officer, a hearing impairment officer, an intellectual disabilities officer, a gender mainstreaming officer, an early childhood education officer, and an adult education officer.

Gender mainstreaming, adult education, and early childhood education were put in the SNIE unit under the restructuring of MINEDUC and REB– but previously, they worked independently. The hearing impairment and intellectual disabilities officers were hired almost a year after I started working in the SNIE unit and shortly before I changed roles. I left before the SNIE director was recruited, and within a year, there had been two acting SNIE directors (the second director started shortly before I left the institution). The SNIE director I worked with also oversaw another unit in a big department. So, for over a year, my workload was that of a disability inclusion specialist, as I provided technical oversight and expertise for all disabilities. It was not an easy role. My initial excitement eventually led to burnout.

As I reflected on this career phase, every memory was colored by a continuous non-stop movement that only made sense as I read William Bridges' book on transition management. Bridges' description of transition management gave me the understanding and vocabulary to

articulate my feelings:

When endings take place, people get angry, sad, frightened, depressed, confused. These emotional states can be mistaken for bad morale, but they aren't. They are signs of grieving, the natural sequence of emotions people go through when they lose something that matters to them. You find them among families that have lost a member, and you find them in an organization where an ending has taken place. (Bridges, 1991, p. 24).

It was a new role for me with different bosses and working with people who were also transitioning. One of my first mistakes was not pausing long enough to reassess and renegotiate based on the situation— I just took what was there and ran with it. In hindsight, I understand there is always wisdom in friction and unease. Most days on the job, especially in the first six months, felt like swimming against the currents.

Now, I know that part of it was grief. My previous role in education had its challenges, but for the most part, I knew what to expect. I worked on a project with a strong leadership team, including a chief of the party, a deputy chief of the party, a technical advisor, a finance director, specialists, and officers. The project was funded by USAID and implemented by an international development agency (my employer) that has operated for over one hundred fifty years. My previous employer provided thorough induction to new employees, had tested and proven ways of doing things, and the overall project was well managed. We had project plans that we followed as a team, with minimal surprise changes throughout.

Things work differently in government agencies as priorities shift and change based on what is happening at the departmental, agency, and ministerial levels. For instance, if there is a shortage of teachers and recruitments are underway, filling teaching positions takes precedence

over others. Multiple invitations are received on any given day or week, requesting the attendance and participation of government officials. Most activities outside the office provide additional incentives for government officials, particularly those conducted out of town, because they provide extra cash or per diem (a daily stipend to cover expenses incurred during fieldwork travel). So, events that are out of town tend to be favored by staff because they can provide additional income. The placement of the SNIE unit is also unique because its purpose is cross-cutting and is directly overseen by the office of the director general (DG) of REB. The whole rationale for creating the unit was for SNIE specialists to work jointly with all three departments at REB to mainstream disability and gender, including (1) Teacher Development, Management, and Career Guidance and Counseling (TDM), (2) Curriculum, Teaching and Learning Resources (CTLR), and (3) ICT in Education. However, each department works independently and is run by a head who reports to the office of the DG.

So, one of the biggest challenges of the SNIE unit was working with all three big departments to ensure that disability is mainstreamed in basic education activities. Disability inclusion is relatively new in the institution. A lot of the programs, plans, and activities were not designed with people with disabilities in mind. Below, I provide an example of how the unit worked with one of the departments, the development, management, career guidance, and counseling, and made some breakthroughs during my employment.

### ***Teacher Capacity***

Most public school teachers have limited training in inclusive education, and teaching assistants or teacher aids are available in a handful of schools. A blind teacher sent a letter requesting accommodations to teach. He wanted a computer and other accessible materials to print

accessible teaching resources. Until this point (a few months into my disability studies graduate program), my focus on inclusive education was on children with disabilities. I had paid no attention to nor did any work with or for teachers with disabilities. This is strange, given that my disability studies professors are disabled women, and I could not imagine better teachers. After reading the letter, I approached a disabled colleague to brainstorm solutions. Uwineza informed me that she knew the teacher and knew their situation well. She also told me that the challenges described in the letter were faced by over thirty teachers with visual impairment in public schools nationwide.

Uwineza was and remains instrumental in advocating for disability rights. She advocated and worked tirelessly with the department in charge of teacher recruitment to make examinations accessible and provide candidates with visual impairments pursuing a career in teaching accommodations, such as extra time and using computers with JAWS, an accessible computer software (a screen reader), to take teaching exams. She reasoned that besides acquiring accessible teaching tools and materials, which she was already working on, we mobilize additional funds and organize training for teachers with visual impairment and their head teachers. I inquired what training she had in mind, to which she replied, “All these teachers have fought very hard to be where they are but do not know their rights. Some do incredible work and use inclusive approaches in their classrooms, while others struggle to navigate the system. Many reported that they do not know what inclusive education is, even when they use inclusive approaches in their teaching practice (World Bank, 2023, 2021). They are simply trying to survive like everyone else. We need to provide training on UNCRPD.”

We agreed to the plan in collaboration with other active inclusive education partners. I mobilized funding, and the training was a big success. We worked collaboratively with the

Rwanda Union of the Blind and the National Council of Persons with Disabilities to develop training materials and work out the training logistics. Another disabled woman, Muhoza (a lawyer by training) and a trainer from Rwanda Union of the Blind joined us to deliver a four-day training on UNCRPD, Accessibility, and the Rights of Teachers with Disabilities at Work. Over twenty-two teachers with visual impairment and twenty-two head teachers were trained (World Bank, 2023). Teachers with visual impairment received computers during the training from REB with JAWS from a civil society organization for persons with disabilities (Ibid). We invited key staff from all three departments of REB to join us and facilitate brief sessions on their department's focus. Three staff from other departments at REB, including TDM and ICT for Education, participated and shared briefly about their specific roles and the work their department does.

The training structure included presentations, panel discussions, plenary discussions, practice exercises, songs, and games. It was conducted openly and interactively, and participants were strongly encouraged to share their experiences and learn from one another, in addition to structured presentations and group activities. We also gave training participants plenty of time to work in groups to build on their understanding of disability and how to remove barriers to the full and equitable participation of teachers and children with disabilities in school. Experienced and high-performing teachers with visual impairment were invited to share effective teaching strategies in a panel discussion, and participants asked questions to understand related concepts better.

During the first week of training, an overview of UNCRPD covered basic concepts around disability, the legal framework for disability rights in Rwanda, barriers to work and employment, and discrimination faced by blind and partially sighted teachers. In the second

week, training focused on how to eliminate discrimination against persons with disabilities, where and how to adjust the school environment and community to be accessible, reduce or eliminate barriers to work and employment of persons with disabilities, best teaching strategies, and reasonable accommodations for blind or partially sighted teachers, practice lessons on mobility and orientation. At the end of the training, every school representative duo (teacher and head teacher) at the workshop was inspired and developed a disability-inclusive programming action plan to implement what they had learned. Their commitments and recommendations are summarized at the end of this chapter.

All participants reported an improved understanding of disability rights and a positive change in attitude toward disability issues (World Bank, 2023). Before the training, only 12 percent of participants understood disability according to the social model of disability (used in UNCRPD), and only 23 percent indicated that they knew how to adjust the school environment based on principles of inclusion. Test scores showed a massive gap in understanding and implementing inclusive education in public schools. During discussions on article 24 of UNCRPD, participants were asked whether they had heard of or knew about the Special Needs and Inclusive Education policy, and none of the forty-two participants knew of it nor knew that there was such a policy. Teacher training colleges have only recently added inclusive education to the curriculum.

The Ministry of Education, with local and international development partners, provides sporadic training (World Bank, 2023). This training is often brief and is not always complemented with practical coaching and resources to improve teachers' knowledge and understanding of disability inclusion in schools (Ibid). Following the training, head teachers reported that the training helped them feel comfortable working with people with disabilities, as

it addressed common stereotypes and fears. They noted that their initial contact was marked with fear and ignorance about disability. Teachers appreciated that the training gave them a forum to voice their grievances and be heard. Staff from the TDM and ICT for Education department reported that the training gave them new insights into the problems and barriers to access and participation of persons with disabilities. The ICT department made a new commitment and started meaningfully engaging us early in key department plans and activities (Ibid).

Negative attitudes and assumptions based on stereotypes and myths about disability are widespread in schools (World Bank, 2023, 2021). Teachers and head teachers hold negative attitudes and assumptions based on stereotypes and myths about disability. Some headteachers, for example, reported that they were scared to engage with persons with disabilities and had, therefore, barely spoken to their teachers with disability. To have adequate training and address these challenges, the training agenda was often revised to include relationship-building activities, and the training on mobility and orientation of blind persons was held sooner rather than later. Furthermore, a significant portion of the first training day discussed barriers faced by persons with disabilities in their communities. Through this activity, persons with disabilities shared their lived and working experiences, including the most significant challenges and microaggressions they face on the job and why their experience differs from that of people without disability.

Storytelling and peer discussions are practical and powerful ways to show the extent to which persons with disability are marginalized and excluded across different areas of life, including education, employment, and community participation. Personal experiences of persons with disabilities are key pedagogical and motivational tools, especially for students with disabilities (Duquette, 2000; Ferri, Keefe, and Gregg, 2001). Stories reveal the incredible empathy of people with disabilities, particularly teachers and youth with disabilities, towards

their students with disabilities. They already know and understand educational barriers and difficulties (Duquette, 2000; Burns and Bell, 2010; Dvir, 2015; Ferri, Keefe, and Gregg, 2001; Riddick, 2003). Many teachers with disabilities revealed that they chose their profession to improve educational practices and promote better learning experiences for children with disabilities. This mirrors research findings that show that the life stories and experiences of teachers with disabilities influence their drive and teaching approach (Duquette, 2000; Ferri, Keefe, and Gregg, 2001).

### ***The Principle of “Nothing About Us with Us”***

Collaborate with persons with disabilities and their organizations to tackle and eliminate systemic barriers to disability inclusion. I was upset at the end of a very long day, and my colleague told me calmly and with a playful chuckle, “Urakaye se wabivamo!” (a Kinyarwanda saying that translates: If you get angry every time, will you ever get out of it!) It is something we say to indicate that something may be endless. We had worked together for months to secure enough resources to train teachers nationwide. We had jointly secured funding for a four-day training, gotten enough laptops for all visually impaired teachers with accessible software (JAWS) installed, prepared training content on UNCRPD and rights of teachers with disability at work, mobilized all blind teachers and their head teachers across the country to attend, gotten two departments at REB and the Rwanda Union of the Blind to facilitate a few sessions with us. We thought everything was in great shape for the workshop. Well, until the group WhatsApp started buzzing with messages the day before the first day of training.

A few teachers arrived early at the venue, introduced themselves, and were turned away by the hotel reception, saying, “We have no hotel booking for you.” The teachers and headteachers were traveling from all corners of the country, and we had limited time. We did not

want to complicate matters further, so we planned to have all participants stay at the hotel where the training would be held. We made hotel bookings for the training venue and rooms for all participants at least three weeks prior. The hotel worked with my employer; two weeks' notice was standard practice. We included details about the number of participants, such as that most participants are blind and would need accessible rooms, preferably on the ground floor. I called the hotel management to ask the teachers to get room and board.

Additionally, we had planned guides for some blind teachers, particularly mothers with babies, and had requested sighted head teachers to assist where necessary (due to budget constraints). We underestimated how poor head teacher-teacher relationships were and how that would affect this arrangement. But as the saying goes, “Where there is a will, there is a way.” Blind teachers showed they were unstoppable. One teacher, whose head teacher had refused to give her a class to teach because they assumed she could not do so because of their disability, planned with other blind and partially blind teachers to travel from their school district to the training venue. The training was not to start until the following day, so we had that evening to get everyone acquainted and settled in before dinner. We contemplated hiring more guides but decided against the idea as my blind and partially blind co-leads felt it was best for the teachers to choose guides with whom they had an existing relationship. Instead, we adjusted our training schedule to start with more mobility orientation training and relationship-building activities to combat negative attitudes towards disability as defined by UNCRPD.

By the time we had dinner, we were all exhausted, and I was still bewildered by the magnitude of discrimination and prejudice. According to UNCRPD, discrimination is the treatment of persons less favorably than another similarly situated person because of characteristics such as disability, race, or sex. Prejudice, conversely, is a “bias which devalues

people because of their perceived membership of a social group” (Abrams, 2010, p. 3). I asked my blind co-leads how they remained unbothered, and they said that this was nothing compared to the discrimination and prejudice that characterized their daily lives since childhood. They both said while chuckling, “We are used to this sha.” I requested the hotel to provide more assistance, especially during mealtimes. The rest of our days there were better, but I was stunned by the initial experience. The overall infrastructure of the hotel was inaccessible. My co-leads, not new to this, woke up early and called the teachers on the first morning to ensure they had everything they needed to start the day. There was a camaraderie that I never saw anywhere else. They all knew each other and shared whatever little resources they had. It also helped that they had all mostly gone to the same private special schools or belonged to the same unions.

### ***Dissemination of SNIE Policy***

Most public education officials have never heard about the SNIE policy, which highlights a massive gap in disseminating the policy and other supporting documents (World Bank, 2023). This further hinders implementation at the grassroots. This gap in policy and implementation was made visible in various activities. For example, in addition to teacher capacity building activities, public dialogues on SNIE policy were held in all four provinces of Rwanda and Kigali. We found that most public servants from the national and village levels needed to be aware of the policy. On average, eight of every ten participants in public dialogues nationwide reported never hearing about the policy for the first time, even though the revised version was passed in 2018. This shows that the SNIE policy has yet to be disseminated from the national level to the school and village levels. This is the case for other documents supporting policy implementation, including the “Child-Friendly Schools” guidelines for school construction and physical accessibility.

***Service Providers and the Media***

Service providers require thorough guidance and tips on how to provide services to persons with disabilities to eliminate prejudice and discrimination. Hotel personnel and other service providers exhibited discriminatory attitudes and prejudice towards persons with disabilities. For example, teachers with disabilities were turned away because hotel personnel did not perceive them as the “right” hotel occupants. Many restaurant servers did not extend the same courtesy to disabled people as they did to others. For example, when blind people were served, their waiters did not ask them what they wanted to eat before serving them. We provided feedback and guided some service providers on how to make their services more accessible (but it was not an organized and targeted activity). By the second week of training, hotel services improved and became slightly more accessible, and participants did not encounter the same barriers as before. Prejudice and negative stereotypes were observed in the media (as elaborated in Chapter One).

***School-Community Partnerships***

There is a need to equip school leaders and teachers with strategies to improve the school working and teaching environment for full access and participation by persons with disabilities (World Bank, 2023). Our teacher training involved head teachers and teachers working together in a practical exercise on step-by-step actions for creating disability-inclusive planning in public schools. Headteachers and teachers identified activities and reasonable accommodations to provide. Following the first week of training, two head teachers mobilized the community to build accessible pathways to the school and home of disabled teachers during Umuganda.

Umuganda is a national holiday for community service held every last Saturday of the month from 8:00 am to 11 am. All businesses are closed in the morning, and residents get

together to do community service, including cleaning, building roads, repairing houses, and other community needs as its members deem necessary through regular meetings. Training participants reported that being aware of barriers faced by persons with disabilities empowered them to mobilize others in the community to make their villages and schools more accessible and accommodating. With the right training and resources, teachers and headteachers can be champions of disability in their communities.

**Below is a summary of action items and commitments made by school representatives following teacher training on UNCRPD and disability inclusion in schools:**

1. Use data collection tools approved by Rwanda Basic Education Board (REB) or the National Council of Persons with Disabilities (NCPD) to collect regular data on children with disabilities in the school and community. Use this data for planning and decision-making to better accommodate children with disabilities at school.
  - a. One practical way this data can be used at the school-level is to identify what examination accommodations individual students need, request REB for them in advance, and prepare students to use them.
2. Establish a local disability mainstreaming working group to share knowledge and experiences about special needs and inclusive education. The group will include the headteacher or teacher in charge of special education needs, a representative(s) from the National Council of Persons with Disabilities, an organization(s) of persons with disabilities, the Disability Mainstreaming Officer, special schools, parent representative(s), and non-governmental organizations.
3. Advocate with the District Education Office and organizations of persons with disabilities for the Ministry of Education to scale the special needs education assessment and referral

nationwide. This will ensure that students with special education needs are provided timely support and referrals to appropriate services.

4. Actively engage the Office of Social Affairs (under the Ministry of Local Government) and the local education stakeholders (under the Ministry of Education) to conduct a needs assessment. Use the findings to design accessible activities and holistically address the education needs of children and teachers with disabilities. Design at least one activity to empower persons with disabilities, starting with providing reasonable accommodations to visual-impaired teachers.
5. Add a budget line and advocate for accessible teaching and learning materials and reasonable accommodations, such as providing teaching assistants for teachers with visual impairments.
  - a. Note: By week two of training, more than five head teachers had identified a way to use existing resources to provide teaching assistants for their teachers with visual impairments.
6. Consult teachers with disabilities during the design, planning, and implementation of school activities. School leaders will ensure that teachers with visual impairments participate meaningfully and take advantage of different leadership opportunities.
7. Build partnerships with organizations of persons with disabilities, including the Rwanda Union of the Blind, the National Council of Persons with Disabilities, non-governmental organizations, and other service providers, to inform activities and provide essential services to students and school staff with disabilities.
8. The school will advocate for and retrofit school structures according to child-friendly school accessibility guidelines and standards provided by the Ministry of Education (2009). It will mobilize community resources to make the school infrastructure accessible (e.g., roads to the

school) for persons with disabilities. According to law number 01/2007 of 20/01/2007, articles 25 and 26, physical buildings, public transport, and communication services are required to be made accessible to persons with disabilities.

- a. By the end of the training, participants had identified things they could do during the monthly community work (“Umuganda”), such as improving roads for easy access and use by persons with disabilities.
9. School leadership will work with local representatives of the National Council of Persons with Disabilities, organizations of persons with disabilities, local village leaders, and other community influencers to raise awareness of disability rights and inclusion through community sensitization campaigns. Invite persons with disabilities to share their lived experiences and discuss disability issues through existing local infrastructure such as Inteko z’Abaturage (citizens assemblies), Umugoroba w’Ababyeyi (Evening of Parents), Inshuti z’Imiryango (Friends of the Family) and other organized community gatherings to discuss disability issues.

## Conclusion

### Reimagining Inclusive Education in Rwanda

“You are only free when you realize you belong no place—you belong every place—no place at all. The price is high. The reward is great,” Maya Angelou told Bill Moyers in a 1973 interview.

I was at a community gathering where we were asked to set individual intentions for the gathering when I realized that belonging was the core recurring theme, highest value, and cross-cut across my data, including personally, academically, and professionally. Instantly, I knew it was the kind of belonging my favorite author, Maya Angelou, alluded to in an interview with Bill Moyers in 1973 (quoted above). The belonging that Brené Brown, another favorite author, describes in her book (2017), “*Braving the Wilderness: The Quest for True Belonging and the Courage to Stand Alone*.” Brené perfectly encapsulates the paradox of Angelou’s words in her book. Belonging starts with self-acceptance and fully encapsulates the feminist definition of agency as self-definition and self-direction.

When I chose autoethnography as my research methodology, I thought I knew what I was signing up for— to systematically describe and analyze my academic and professional experiences to provide a nuanced and culturally grounded understanding of inclusive education in Rwanda. Early in my cultural anthropology and women studies courses, I learned that “the personal is political” and the critical need for self-reflexivity for self-actualization and social transformation. Like bell hooks, one of my favorite scholars, I was concerned by the absence of research centering on local practitioner narratives by Rwandan women or African scholars on inclusive education. Most of the research on inclusive education is based in Western countries

and done by Western scholars. There is hardly any research that integrates theoretical discussion, practical interventions, and advocacy efforts for the full inclusion of children with disabilities in Rwandan classrooms (or even Sub-Saharan Africa). I took a quote from Toni Morrison's interview at the New York Public Library in 2013 to heart when I first read it as an undergraduate student: "If there is a book that you want to read, but it hasn't been written yet, then you must write it." I knew I wanted to tell stories about our lived experiences for actionable, equity-focused, and localized interventions in inclusive education.

However, I was surprised by the emotional labor that came with this work. I did not know how heavy and hard reliving these stories would be as I wrote and analyzed their meaning. It was like going to therapy and playing both the role of the therapist and the client. As the client, I reflected on memorable incidents and described them. I then unpacked what they meant. Sometimes, I broke down and cried and was forced to take 'unplanned breaks.' The therapeutic—after I understood the meaning of different emotions as they arose during my reflection—nature of this process initially made me question whether this was even 'scholarly.' I realized late in the process that the "stuckness" and "heaviness" I felt came from my rejection of the emotional experience and fought to separate the subject and researcher. I often felt defensive and judgmental of my work, making it difficult to stay on task and accomplish this project. What sustained me was the determination to help others understand and manage change and transition to a world where every child, including the one with a disability, can belong, learn, and flourish.

Reading works by some of my favorite scholars in various disciplines, including (1) bell hooks (1984), Audre Lorde (2016), and Marilyn Frye (1983) on feminist theory and practice; (2) Paulo Freire (1993) and Paul Abberley (1987) on oppression and liberation; Brené Brown (2010,

2017) on true belonging and the power of vulnerability through storytelling; (3) Gordon Neufeld (2012) and Deborah MacNamara (2016) on child development and attachment theory; (4) and Carolyn Ellis (1995) on doing autoethnography proved to be a great companion to wade through the wild of uncertainty, vulnerability, and criticism. They gave me the courage to stand alone until I eventually heard what Maya Angelou told Brené Brown (2024) when they first met on the Oprah show, as if she was talking to me, “You’re doing important work. Keep doing it. Keep talking about your work. Don’t stop, and don’t let anyone get in the way.”

Autoethnography proved to be an effective methodology for this thesis because it allows researchers to embody the tenets of belonging, a key theme in my data. It forced me to 1) move in and get close and personal. According to Brene’s research findings, “people are hard to hate close up” (Brown, 2017). Currently, the most significant barrier to persons with disabilities in Rwanda is attitudinal. Negative attitudes towards persons with disability manifest in stigma, discrimination, and hate. Graduate school, in particular, the field of disability studies, helped me see and gave me tools to unlearn socialized and internalized ‘hatred’ and fear of disability or anything “other.” The devotion of anti-oppression transformative thinkers like Paulo Freire, bell hooks, and Audre Lorde to critical consciousness taught me the power of education for liberation. In particular, Freire’s call for the combination of dialogue and critical consciousness helped me see inclusion as a continuous journey of reflection and action upon reality to transform it (1993, p. 38).

An examination of Rwanda’s history through a postcolonial lens and the historical development of disability in chapter one reveals the social features of disability as oppression. Taking a deep dive into oppression led me to examine power, belonging, and agency, as it forced

me to reflect on my privilege and positionality as a professional and scholar. Ultimately, this helped me understand the value of speaking truth to power (the second tenant of belonging) as a necessary bridge to ‘hold hands with strangers’ (the third tenant of belonging).

A close review of inclusion and inclusive education highlighted the need for equity to address systemic barriers and ensure that all children, including children with disabilities, get access to quality education. Some people are disadvantaged more than others due to various intersections of class (poverty), sex, disability, and age, among other social identity markers. Reclaiming Rwandan traditional values rooted in Ubuntu philosophy (solidarity and humanism) aligns with practices required to advance equity (resource allocation). An examination of the medical and social model of disability shows that social barriers, not impairments, create disability. Disability is a social construct shaped by historical, cultural, and systemic factors. Therefore, inclusive education is a key pathway to remove these barriers.

In chapters two and three, I step into the real world of Rwandan classrooms and communities and policy discussion. The goal is to “Hold hands. With strangers” (Brown, 2017). Oppression in various forms teaches us to negotiate our worth with the world. People with disabilities, including children, are daily made to feel less than others, and without knowing it, the oppressor is also dehumanized as they dehumanize others. My Rwandan upbringing, professional experience, and academic pursuits have all shown me that human beings are interrelated. What you do to another, you do to yourself. We were all created equal; thus, our policies and actions should reflect this fact. Like the Ubuntu saying goes, “I am because we are.”

## **Implications for Policy and Practice**

### ***Policy Recommendations***

1. Address the colonial legacy of segregation by emphasizing inclusive communities of belonging tied to Rwandan values of solidarity and humanism and an incremental phasing of special schools into disability resource hubs.
2. Ministry of Education, Ministry of Local Government, and National Child Development Agency should work together with organizations of persons with disabilities to strengthen school-community partnerships through existing local infrastructure, such as Umuganda, Umugoroba w'Ababyeyi, Ishuti z'Umuryango, to ensure caregivers of children with disabilities and adults with disabilities are supported to enroll and complete school. 'It takes a village to raise a child' (African proverb).
3. The Ministry of Finance should increase the budget for education, with a set budget for disability inclusion, to ensure equitable resource allocation to schools. This would account for the diverse needs of the school population, including strengthening teacher training and capacity-building in inclusive education.

### *Practical Steps*

1. Government agencies should work with development partners, both local and international, to scale up advocacy and community mobilization efforts.
2. Rwanda Basic Education Board should implement inclusive curriculum reforms, provide a budget line for reasonable accommodations, and invest more in assistive technologies.
3. The Ministry of Education should invest in scaling up construction projects to retrofit schools for physical accessibility using universal design principles as per the "child-friendly school guidelines."

4. The Ministry of Education and Rwanda Basic Education Board should foster collaboration between the government, NGOs, and communities for holistic inclusion by strengthening disability inclusion working groups at the national level and disability inclusion communities of practice at the school or village level.
5. Government agencies and development partners should invest in longitudinal studies, led by Rwandan and African scholars, on the long-term impact of inclusive education interventions on learning outcomes and community attitudes.
6. Government agencies, development partners, and researchers should investigate the intersection of disability with other markers of disadvantage, such as gender and poverty. All projects and social mechanisms should be designed and implemented using the lens of intersectionality.

### References

- Abberley, P. (1987). The concept of oppression and the development of a social theory of disability. *Disability, Handicap & Society*, 2(1), 5-19.  
<https://doi.org/10.1080/02674648766780021>
- Abrams, K. (1999). From autonomy to agency: Feminist perspectives on self-direction. *William and Mary Law Review*, 40(3), 805-846.  
<https://scholarship.law.wm.edu/wmlr/vol40/iss3/6>
- Ainscow, M. (2005). Developing inclusive education systems: What are the levers for change? *Journal of Educational Change*, 6(2), 109-124. <https://doi.org/10.1007/s10833-005-1298-4>
- Ainscow, M. (2020). Promoting inclusion and equity in education: lessons from international experiences. *Nordic Journal of Studies in Educational Policy*, 6(1), 7-16.  
<https://doi.org/10.1080/20020317.2020.1729587>
- Antoninis M., & Montoya, S. (2022, September 22). New measurement shows that 244 million children and youth are out of school. *World Education Blog*. <https://world-education-blog.org/2022/09/01/new-measurement-shows-that-244-million-children-and-youth-are-out-of-school/>
- Antoninis, M., April, D., Barakat, B., Bella, N., D'Addio, A. C., Eck, M., & Zekrya, L. (2020). All means all: An introduction to the 2020 Global Education Monitoring Report on inclusion. *Prospects*, 49, 103-109. <https://https://doi.org/10.1007/s11125-020-09505-x>

Ananian, S., & Dellaferrera, G. (2024). *A study on the employment and wage outcomes of people with disability* [ILO Working paper 124]. International Labour Organization.

<https://www.ilo.org/publications/study-employment-and-wage-outcomes-people-disabilities>

Auden, W H. (1938). *Funeral blues*. <https://allpoetry.com/funeral-blues>

Barnes, C., & Mercer, G. (2004). The Social Model, the Emancipatory Paradigm and User Involvement. In *‘Implementing the Social Model of Disability: Theory and Research*. The Disability Press.

Barnes, C., & Mercer, G. (2004). The Social Model, the Emancipatory Paradigm and User Involvement. In *‘Implementing the Social Model of Disability: Theory and Research*. The Disability Press.

Barnes, C. (1991). *Disabled People in Britain*. Hurst and Company.

Banks, P., Kuper, H., & Polack, S. (2018). Poverty and disability in low- and middle- income countries: A systematic review. PLOS ONE 13(9): e0204881.

<https://doi.org/10.1371/journal.pone.0204881>

Bergin, C., & Bergin, D. (2009). Attachment in the classroom. *Educational Psychology Review*, 21(2), 141–170. <https://doi.org/10.1007/s10648-009-9104-0>

Baumer, N., & Frueh, J. (2021, November 23). What is neurodiversity? *Harvard Health Publishing*. <https://www.health.harvard.edu/blog/what-is-neurodiversity-202111232645>

Booth, T., & Ainscow, M. (2002). *Index for inclusion: developing learning and participation in schools* (C. M. Vaughan, Ed.). Centre for Studies on Inclusive Education (CSIE).

Bots, E. 2015. *The right to education: Challenges and perspectives on inclusive primary education for children with disabilities in Rwanda* [Master's thesis, University of Vienna]. <http://dx.doi.org/10.25330/1766>

Braun, V., & Clarke, V. (2012). Thematic analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbook of research methods in psychology, vol.2: Research designs: Quantitative, qualitative, neuropsychological, and biological* (pp. 57-71). American Psychological Association.

Bradshaw, J. (1992). *Homecoming: Reclaiming and healing your inner child*. Bantam Books.

Brown, B. (2010). *The gifts of imperfection: Letting go of who you think you are supposed to be to embrace who you are*. Hazelden.

Brown, B. (2017). *Braving the wilderness: The quest for true belonging and the courage to stand alone*. Random House.

Brown, B. (n.d.). Research. Brené Brown. Retrieved on January 11, 2024, from <https://brenebrown.com/the-research/>

Bridges, W. (1991). *Managing transitions: Making the most of change*. Addison-Wesley Publishing Company, Inc.

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101. <https://doi.org/https://doi.org/10.1191/1478088706qp063oa>
- Braun, V., & Clarke, V. (2020). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*.  
<https://doi.org/https://doi.org/10.1080/14780887.2020.1769238>
- Burnier, D. (2006). Encounters with the self in social science research: A political scientist looks at autoethnography. *Journal of Contemporary Ethnography*, 35(4), 410-418.  
<https://doi.org/10.1177/0891241606286982>
- Burns, E., & Sheena, B. (2010). “Voices of Teachers with Dyslexia in Finnish and English Further and Higher Educational Settings.” *Teachers and Teaching* 16 (5), 5-19.
- Cambridge Dictionary. (2024). Inclusion. In *Cambridge Dictionary*. Retrieved January 10, 2024, from <https://dictionary.cambridge.org/dictionary/english/inclusion>
- Chemonics. (2021). *Final report: USAID Soma Umenye*. Author. <https://chemonics.com/wp-content/uploads/2022/05/Final-Report-Soma-Umenye.pdf>
- Christopher, S. (2019). Touch hypersensitivity in children with autism - An analysis. *IJRAR - International Journal of Research and Analytical Reviews* 6(2), 616-622.
- Cleall, Esme. (2015). *Orientalising deafness: Race and disability in imperial Britain*. *Social Identities* 21(1): 22-36. DOI: 10.1080/13504630.2014.995348
- Cologon, K. (2014). *Inclusive education in the early years*. Oxford University Press.

Codes and Laws of Rwanda of 20/01/2007, Pub. L. No. 01/2007, Relating to Protection of Disabled Persons in General (2007).

[https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/11/Rwanda\\_Law-Relating-to-Protection-of-Disabled-Persons-in-General.pdf](https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/11/Rwanda_Law-Relating-to-Protection-of-Disabled-Persons-in-General.pdf)[https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/11/Rwanda\\_Law-Relating-to-Protection-of-Disabled-Persons-in-General.pdf](https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/11/Rwanda_Law-Relating-to-Protection-of-Disabled-Persons-in-General.pdf)

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *University of Chicago Legal Forum*, 1(8), 138-167.

<https://chicagounbound.uchicago.edu/uclf/vol1989/iss1/8>

Critz, C., Blake, K., & Noguiera, E. (2015). Sensory processing challenges in children. *The Journal for Nurse Practitioners*, 11(7), 710-716.

<https://doi.org/10.1016/j.nurpra.2015.04.016>

Driedger, D. (Ed.) (2021). *Still living the edges: A disabled women's reader*, ed. Inanna Publications.

Duquette, Cheryll. 2000. "Examining Autobiographical Influences on Student Teachers with Disabilities." *Teachers and Teaching* 6 (2): 215–228.

Dvir, Nurit. 2015. "Does Physical Disability Affect the Construction of Professional Identity? Narratives of Student Teachers with Physical Disabilities." *Teaching and Teacher Education* 52: 56–65.

- Ellis, C. (1995). *Final negotiations: A story about love, loss, and chronic illness*. Temple University Press.
- Ellis, C. (1999). Heartful autoethnography. *Qualitative Health Research*, 9(5), 669–683.  
<https://doi.org/10.1177/104973299129122153>
- Ellis, C., Adams T. E., & Bochner A. P. (2011). Autoethnography: An Overview. *Historical Social Research*, 36(4), 273-290. <https://doi.org/10.17169/fqs-12.1.1589>
- Freire, P. (1993). *Pedagogy of the oppressed*. Continuum.
- Ferri, Beth A., Charlotte H. Keefe, and Noel Gregg. 2001. “Teachers with Learning Disabilities: A View from Both Sides of The Desk.” *Journal of Learning Disabilities* 34 (1): 22–32.  
<https://doi.org/10.1177/002221940103400103>
- Frye, M. (1983). Oppression. In *The politics of reality: Essays in feminist theory*, (pp. 1-16). Crossing Press.
- Galler, J. R., Bryce, C. P., Waber, D. P., Hock, R. S., Harrison, R., Eaglesfield, G. D., & Fitzmaurice, G. (2012). Infant malnutrition predicts conduct problems in adolescents. *Nutritional Neuroscience*, 15(4), 186-192.  
<https://doi.org/10.1179/1476830512Y.0000000012>
- Galler, J. R., Bryce, C. P., Zichlin, M. L., Fitzmaurice, G., Eaglesfield, G. D., & Waber, D. P. (2012). Infant malnutrition is associated with persisting attention deficits in middle adulthood. *The Journal of Nutrition*, 142(4), 788-794.  
<https://doi.org/10.3945/jn.111.145441>

Gladstone, M. (2010). A review of the incidence and prevalence, types and aetiology of childhood cerebral palsy in resource-poor settings. *Annals of Tropical Paediatrics*, 30(3), 181-196. <https://doi.org/10.1179/146532810X12786388978481>

Ministry of Local Government. (2021). *National Policy on Persons with Disabilities*. Republic of Rwanda.  
[https://www.minaloc.gov.rw/fileadmin/user\\_upload/Minaloc/National\\_Policy\\_on\\_Disability\\_and\\_Inclusion\\_final.pdf](https://www.minaloc.gov.rw/fileadmin/user_upload/Minaloc/National_Policy_on_Disability_and_Inclusion_final.pdf)

Hawkins, J. (2021). Deaf out loud. In Driedger, D (Ed.), *Still living the edges: A disabled women's reader*, (pp. 14-17). Inanna Publications.

hooks, b. (1984). *Feminist theory: From margin to center*. South End Press.

Hodge, M., Bolinas, A., Jaucian, E., Boneo, R., Schapira, A., Villanueva, M. M. V. (2017). Cross-sectional survey to assess prevalence of disability and access to services in Albay Province, the Philippines. *Disability, CBR & Inclusive Development*, 28(3), 5-31.  
<https://dcidj.uog.edu.et/index.php/up-j-dcbrid/article/view/266>

Horner, R. (2020). Towards a new paradigm of global development? Beyond the limits of international development. *Progress in Human Geography*, 44(3), 415–436.  
<https://doi.org/10.1177/0309132519836158>

Habimfura, I. (2023, May 15). Rwanda is leading the way for an orphan free Africa. Hope and Homes. <https://www.hopeandhomes.org/blog/rwanda-is-leading-the-way-for-an-orphanage-free-africa/>

IMF. (2023, August 10). *Rwanda: Datasets*.

<https://www.imf.org/external/datamapper/profile/RWA>

*Interview with Jean Philippe Rapp conducted in 1985: Dare to invent the future.* (n.d.). Thomas

Sankara. Retrieved June 10, 2024, from [https://www.thomassankara.net/interview-de-](https://www.thomassankara.net/interview-de-jean-philippe-rapp-realise-en-1985-oser-inventer-lavenir/#)

[jean-philippe-rapp-realise-en-1985-oser-inventer-lavenir/#](https://www.thomassankara.net/interview-de-jean-philippe-rapp-realise-en-1985-oser-inventer-lavenir/#)

Kagame, P. (2016, December 4). *This is about making sure you know you are important to us*

*and your education is our priority* [Facebook page]. Retrieved August 8, 2024, from

[https://www.facebook.com/PresidentPaulKagame/posts/this-is-about-making-sure-you-](https://www.facebook.com/PresidentPaulKagame/posts/this-is-about-making-sure-you-know-you-are-important-to-us-and-your-education-is/10153873957422282/)

[know-you-are-important-to-us-and-your-education-is/10153873957422282/](https://www.facebook.com/PresidentPaulKagame/posts/this-is-about-making-sure-you-know-you-are-important-to-us-and-your-education-is/10153873957422282/)

Karangwa, E. (2004). Developments in the situation of the people with disabilities in Rwanda.

*PHOS-Newsletter inclusive of 2004-10-15.*

[http://www.phos.be/Engels/basisframe\\_engels.htm](http://www.phos.be/Engels/basisframe_engels.htm)

Karangwa, E., Ghesquière, P. & Devlieger, P. (2007). The Grassroots community in the

vanguard of inclusion: The post-genocide Rwandan prospects. *International Journal of*

*Inclusive Education*, 11(5-6), 607-626. <https://doi.org/10.1080/13603110600790340>

Karangwa, E. (2006). *Grassroots Community-Based Inclusive Education: Exploring educational*

*prospects for young people with disabilities in the post-conflict Rwandan communities*

(Publication No. 1792781) [Doctoral dissertation, Katholieke Universiteit Leuven].

<https://kuleuven.limo.libis.be/discovery/fulldisplay?docid=lirias1792781&context=Searc>

[hWebhook&vid=32KUL KUL:Lirias&lang=en&search\\_scope=lirias\\_profile&adaptor=SearchWebhook&tab=LIRIAS&query=any,contains,LIRIAS1792781&offset=0](https://www.ajol.info/index.php/rje/article/view/111568)

Karangwa, E., Daniel, I., and Agnes M. (2013). Plight of learners with visual impairments in Rwandan science classes: evidencing teachers' practice in HVP Gatagara. *Rwandan Journal of Education*, 1(2), 19-37.

<https://www.ajol.info/index.php/rje/article/view/111568>

Kagire, L. M. (2022, March 23). Speech and hearing impaired Miss Rwanda contender on braving all of life's odds. *The New Times*.

<https://www.newtimes.co.rw/article/194492/Lifestyle/speech-and-hearing-impaired-miss-rwanda-contender-on-braving-all-of-lifeasodds>

Kerac, M., Postels, D. G., Mallewa, M., Alusine Jalloh, A., Voskuijl, W. P., Groce, N., Gladstone, M., & Molyneux, E. (2014). The interaction of malnutrition and neurologic disability in Africa. *Seminars in Pediatric Neurology*, 21(1), 42-49.

<https://doi.org/10.1016/j.spen.2014.01.003>

Knowles, S. (2017). *A Seat at the Table* [Album]. Saint; Columbia.

Lee, J., Meijer, E., Phillips, D. Hu, P. (2021). Disability incidence rates for men and women in 23 countries: Evidence on health effects and gender. *The Journals of Gerontology: Series A*, 76(2), 328-338. <https://doi.org/10.1093/gerona/glaa288>

- Liao, J., & Zhao, J. (2013). Rate of returns to education of persons with disabilities in rural China. *A paper presented at the international conference on applied social science research*. <https://dx.doi.org/10.2991/icasr.2013.60>
- Lorde, A. (1984). *Sister outsider: Essays and speeches*. Crossing Press.
- Lorde, A. (2016). *Sister outsider: Essays and speeches* (Eller, R, Narr) [Audiobook]. Audible. Tantor Audio.
- Lorde, A. (1978, August 25). *Uses of the erotic: The erotic as power* [Conference presentation]. Fourth Berkshire Conference on the History of Women, Mount Holyoke College, Massachusetts, NE, United States. [https://www.centraeurasia.org/wp-content/uploads/2023/02/audre\\_lorde\\_cool-beans.pdf](https://www.centraeurasia.org/wp-content/uploads/2023/02/audre_lorde_cool-beans.pdf)
- Lutter, C. K., & Lutter, R. (2012). Fetal and early childhood undernutrition, mortality, and lifelong health. *Science*, 337(6101), 1495-1499. DOI: 10.1126/science.1224616
- MacNamara, D. (2016). *Rest, play, grow: Making sense of preschoolers (or anyone who acts like one)*. Aona Books.
- Malkki, L. H. (1995). Refugees and exile: From “Refugee Studies” to the national order of things. *Annu. Rev. Anthropol.*, 24:495-523. <http://www.jstor.org/stable/2155947>
- Malik, A. A., & Nadeem, M. (2022). Community-Based Rehabilitation (CBR) and its Impact on Quality of Life (QoL) of Disabled Children. *Review of Education, Administration and Law*, 5(4), 519-532. <https://doi.org/10.47067/real.v5i4.267>

Mattingly, J., and Suubi, P. (2015). A study on children with disabilities and their right to education. *The Republic of Rwanda, Education Development Trust, UNICEF.*

<https://www.unicef.org/esa/reports/study-children-disabilities-and-their-right-education-rwanda>

Moyo, P. (2012). Access to education for children with disabilities in Uganda: Implications for education for all. *Journal of International Education and Leadership*, 2(2), 2161-7252.

<https://files.eric.ed.gov/fulltext/EJ1136042.pdf>

Mora, M. E., Orellana, S. S., & Freire, G. (2021). Disability inclusion in Latin America and the Caribbean: A path to sustainable development. *World Bank.*

<https://documents1.worldbank.org/curated/en/099015112012126833/pdf/P17538305622600c00bf3f09659df1f2f79.pdf>

Ministry of Education. (2023). The 2023/2024 Forward-Looking Joint Review of the Education Sector. Republic of Rwanda.

<https://www.mineduc.gov.rw/index.php?eID=dumpFile&t=f&f=72437&token=c8976b0b0de2a4097bff30fad8dde226f7e868f8>

Ministry of Education. (2018). *Special Needs and Inclusive Education Policy*. Republic of Rwanda.

<https://www.mineduc.gov.rw/index.php?eID=dumpFile&t=f&f=5823&token=30ac75706c41dd0b8f196645c969d2ddcf928d99>

Ministry of Education. (2018). Education Sector Strategic Plan 2018/19 to 2023/24. Republic of Rwanda.

[https://planipolis.iiep.unesco.org/sites/default/files/ressources/rwanda\\_esp\\_2018-19-2023-24.pdf](https://planipolis.iiep.unesco.org/sites/default/files/ressources/rwanda_esp_2018-19-2023-24.pdf)

Ministry of Education. (2009). *Child Friendly Schools Infrastructure Standards and Guidelines: Primary and Tronc Commun Schools*. Republic of Rwanda.

[https://www.preventionweb.net/files/15377\\_rwandachildfriendlyschoolsinfrastru.pdf](https://www.preventionweb.net/files/15377_rwandachildfriendlyschoolsinfrastru.pdf)

Mandela, N. (2006). Foreword. In R. J. Khoza (Ed.), *Let Africa lead: African transformational leadership for 21st century business* (pp. 6). Vezubuntu.

Moloketi, G. R. (2009). Towards a common understanding of corruption in Africa. *Public Policy and Administration*, 24(3), 331-338. <https://doi.org/10.1177/095207670910381>

Mutezigaju, F., Wamocho I. F., and Bunyasi A. B. (2019). Assessment accommodations as predictors of academic achievement of learners with physical disabilities in Rwanda. *IOSR Journal of Research & Method in Education* 9(4), 1-26. DOI: 10.9790/1959-0904031926

National Institute of Statistics of Rwanda. (2022). *5<sup>th</sup> Rwanda population and housing census*. <https://www.statistics.gov.rw/publication/key-figures-5th-rwanda-population-and-housing-census-phc>

National Institute of Statistics of Rwanda (NISR), Rwanda Ministry of Health, ICF. (2021).

*Rwanda Demographic and Health Survey 2019-2020: Final Report*. NISR and ICF.

[https://www.statistics.gov.rw/dhs\\_Rwanda\\_2020](https://www.statistics.gov.rw/dhs_Rwanda_2020)

Neufeld, G. (2012, November 13). Keys to the well-being of children and youth. Neufeld

Institute. [https://neufeldinstitute.org/wp-](https://neufeldinstitute.org/wp-content/uploads/2017/12/Neufeld_Brussels_address.pdf)

[content/uploads/2017/12/Neufeld\\_Brussels\\_address.pdf](https://neufeldinstitute.org/wp-content/uploads/2017/12/Neufeld_Brussels_address.pdf)

Njelesani, J., Siegel, J., & Ullrich, E. (2018). Realization of the rights of persons with disabilities

in Rwanda. *PLOS ONE*, *13*(5), e0196347. <https://doi.org/10.1371/journal.pone.0196347>

Oliver, Mike. (2013). The social model of disability: thirty years on. *Disability & Society*, *28*(7),

1024-1026

Oliver, Mike. (2004). The Social Model in Action: If I had a hammer. In Barnes, C., & Mercer,

G (Eds.), *Implementing the social model of disability: Theory and research* (pp. 18-31).

The Disability Press.

One Just World. (2013). *Rosangela Berman Bieler on the poverty and disability cycle*.

YouTube. <https://www.youtube.com/watch?v=ZQvOp9SKnDc>

O'Toole, B. (1991). Guide to Community-Based Rehabilitation Services. *UNESCO*.

<https://unesdoc.unesco.org/ark:/48223/pf0000090458>

Oxford English Dictionary. (2024). Inclusion. In *Oxford English Dictionary*. Retrieved

September 30, 2024, from <https://doi.org/10.1093/OED/9474685541>.

Pellicano, L., Bölte, S., & Stahmer, A. (2018). The current illusion of educational inclusion.

*Autism*, 22(4), 386-387. <https://doi.org/10.1177/1362361318766166>

Penido, A. B., Rezende, G. H. S., Abreu, R. V., de Oliveira, A. C. P., Pereira, G. S., & Moraes,

M. F. D. (2012). Malnutrition during central nervous system growth and development

impairs permanently the subcortical auditory pathway. *Nutritional neuroscience*, 15(1),

31-36. <https://doi.org/10.1179/1476830511Y.0000000022>

Phamondon, K., Shahram, S. (2024). Defining equity, its determinants, and the foundations of

equity science. *Social Science & Medicine* 351, 1-9.

Rwelamila, P. D., Talukhaba, A. A., & Ngowi, A. B. (1999). Tracing the African project failure

syndrome: The significance of 'ubuntu.' *Engineering Construction and Architectural*

*Management*, 6(4), 335-346. <https://doi.org/10.1046/j.1365-232x.1999.00120.x>

Save the Children. (2019). 100 years for children. [https://www.savethechildren.net/about-us/100-](https://www.savethechildren.net/about-us/100-years-children)

[years-children](https://www.savethechildren.net/about-us/100-years-children)

Save the Children. (2020). Mureke Dusome impact evaluation endline report: Program impact on

literacy knowledge, attitudes, and practices. USAID.

[https://pdf.usaid.gov/pdf\\_docs/PA00X74N.pdf](https://pdf.usaid.gov/pdf_docs/PA00X74N.pdf)

Said, E. W. (1978). *Orientalism*. Routledge & Kagan Paul.

[https://sites.evergreen.edu/politicalshakespeares/wp-](https://sites.evergreen.edu/politicalshakespeares/wp-content/uploads/sites/33/2014/12/Said_full.pdf)

[content/uploads/sites/33/2014/12/Said\\_full.pdf](https://sites.evergreen.edu/politicalshakespeares/wp-content/uploads/sites/33/2014/12/Said_full.pdf)

Save the Children. (2020). Mureke Dusome quarterly report quarter 4, fiscal year 2020 period:

July - September 2020. USAID. [https://pdf.usaid.gov/pdf\\_docs/PA00X3Z8.pdf](https://pdf.usaid.gov/pdf_docs/PA00X3Z8.pdf)

Save the Children. (2021). Mureke Dusome: Final Report. USAID.

[https://pdf.usaid.gov/pdf\\_docs/PA00Z65S.pdf](https://pdf.usaid.gov/pdf_docs/PA00Z65S.pdf)

Shapiro, A. (2016, November 11). *'We've always had a seat at the table': Solange on*

*conversations that heal*. NPR. <https://www.npr.org/transcripts/501165834>

Shakespeare, T., & Watson, N. (2002). The social model of disability: an outdated ideology?

*Research in Social Science and Disability*, 2, 9-28. <https://doi.org/10.1016/S1479->

[3547\(01\)80018-X](https://doi.org/10.1016/S1479-3547(01)80018-X)

Swartz, L. (2014). Five Challenges for Disability-Related Research in Sub-Saharan Africa.

*African Journal of Disability*, 3(2), 1–6.

Shakespeare, T., & Watson, N. (2002). The social model of disability: an outdated ideology?

*Research in Social Science and Disability*, 2, 9-28.

[https://www.um.es/discatif/PROYECTO\\_DISCATIF/Textos\\_discapacidad/00\\_Shakespeare2.pdf](https://www.um.es/discatif/PROYECTO_DISCATIF/Textos_discapacidad/00_Shakespeare2.pdf)

Shire, W. (2015). *What they did yesterday afternoon*. [https://verse.press/poem/what-they-did-](https://verse.press/poem/what-they-did-yesterday-afternoon-6524900794187889060)

[yesterday-afternoon-6524900794187889060](https://verse.press/poem/what-they-did-yesterday-afternoon-6524900794187889060)

Shakespeare, T., & Watson, N. (2010). Defending the social model. *Disability & Society*, 12(2),

293-300. <https://doi.org/10.1080/09687599727380>

Steinmetz, K. (2020, February 20). She coined the term ‘intersectionality’ over 30 years ago.

Here’s what it means to her today. *Time*. <https://time.com/5786710/kimberle-crenshaw-intersectionality/>

Thompson, D. (2001). *Radical feminism today*. SAGE Publications.

Travers, J. (2018). What is resource equity? A working paper that explores the dimensions of resource equity that support academic excellence. *U.S. Department of Education: Education Resource Strategies*. <https://files.eric.ed.gov/fulltext/ED593369.pdf>

Tutu, D. (2004). *God has a dream: A vision of hope for our future*. Rider.

UNESCO. (1994). *Final report: World conference on special needs education: Access and quality*. Author. <https://unesdoc.unesco.org/ark:/48223/pf0000110753>

UNESCO. (2015). *Incheon declaration and framework for action towards inclusive and equitable quality education and lifelong learning for all*. Author.  
<https://iite.unesco.org/publications/education-2030-incheon-declaration-framework-action-towards-inclusive-equitable-quality-education-lifelong-learning/>

UNESCO. (2017). *A Guide for Ensuring Inclusion and Equity in Education*. Author.  
<https://doi.org/10.54675/MHHZ2237>

UNICEF. (2021). *Seen, counted, included: Using data to shed light on the well-being of children with disabilities*. Author. <https://data.unicef.org/resources/children-with-disabilities-report-2021/>

UNICEF. (2023). *Country Office Annual Report 2023: Rwanda*. Author.

<https://www.unicef.org/media/152281/file/Rwanda-2023-COAR.pdf>

UNICEF. 2022. Education Budget Brief: Investing in Child Education in Rwanda 2022/2023.

<https://www.unicef.org/rwanda/media/4596/file/Education-Budget-Brief-2022-2023.pdf>

UNICEF. (2024, October 14). *Nearly two million severely malnourished children at risk of death due to funding shortages for therapeutic food* [Press release].

<https://www.unicef.org/press-releases/nearly-two-million-severely-malnourished-children-risk-death-due-funding-shortages>

USAID Rwanda. (2020). *Quarterly Program Report: USAID Soma Umenye Project*. Author.

[https://pdf.usaid.gov/pdf\\_docs/PA00X74N.pdf](https://pdf.usaid.gov/pdf_docs/PA00X74N.pdf)

United Nations. (2015). *Transforming our World: The 2030 Agenda for Sustainable Development*. Author. <https://sdgs.un.org/2030agenda>

United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. Author.

<https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

Uwezo Kenya. (2016). *Are our children learning? Literacy and numeracy across East Africa*.

Twaweza. <https://twaweza.org/wp-content/uploads/2021/02/2013-Annual-Report-Final-Web-version.pdf>

WHO & UNICEF. (2015). *Assistive technology for children with disabilities: Creating opportunities for education, inclusion, and participation. A discussion paper.* World Health Organization. <https://www.unicef.org/media/126246/file/Assistive-Tech-Web.pdf>

World Bank. (2021). *A landscaper review of ICT for disability-inclusive education.* Author. <https://documents1.worldbank.org/curated/en/099840001312211991/pdf/P17136805cfd1f074095390cb6b01c0c715.pdf>

World Bank. (2023). *Inclusive education in Rwanda: A final report of project activities.* Author. <https://documents1.worldbank.org/curated/en/099052323105539110/pdf/P1733020a9504a05c0a73801245c164256d.pdf>

## Appendix A

### Journal Entry: Disability and Poverty

October 26, 2022

Personal Response to “Rosangela Berman Bieler on the poverty and disability cycle,” by One Just World. Retrieved from: <https://www.youtube.com/watch?v=ZQvOp9SKnDc>

In this video, Rosangela Bieler explains the interplay between poverty and disability. She starts by giving us a brief biography to explain the impact of poverty on disabled people. She was born to a middle-class family in Rio de Janeiro, Brazil. Bieler had an accident at the age of 18, which disabled her, but this did not prevent her from completing her Undergraduate degree and then doing a Master’s degree, getting married, giving birth to a child, and traveling around the world. This is because her family had the financial means to get her to rehabilitation and invest in her education. She juxtaposes her life to that of other adults with the same disability living in slums in her neighborhood who get about a year to live at most. In other words, Bieler may not have survived had she been born in a poor household. This disparity in life chances/survival rates is unfair and points to the relationship between poverty and disability. It is a cycle that feeds itself, as Bieler rightly pointed out.

Poverty causes disability, and disability also causes poverty. How does this happen? Bieler needed rehabilitation and other medical treatment, which is usually expensive and, therefore, inaccessible to people living below or on the poverty line. For those who get treatment, it usually comes at a great cost to the entire family, worsening their living conditions (putting them deeper into the poverty cycle) and worsening their health chances and well-being. Those who do not get treatment die prematurely, or their disability worsens over time. Furthermore,

their chances of acquiring quality education and employment are low compared to their non-disabled and financially secure peers, further exacerbating their exclusion. As highlighted in the video, 100 million children are disabled due to malnutrition, which is not surprising because the majority of disabled people live in low-income countries. While the majority of the world's population is situated in the global South, poverty and wars (largely funded and kept going by Western, high-income countries) also increased disability numbers. The increased cost of living for disabled people needs to be factored into the development framework, including social protection, poverty alleviation, and emergency initiatives.

Bieler also references the Millennium Development Goals' (MDGs) success and its continuation through the Sustainable Development Goals to eliminate poverty and improve living standards for all. Yet, the objectives of SDGs cannot be reached if poverty alleviation programs leave persons with disabilities behind. Disability is featured in the SDGs (unlike in the MDGs) and there is more push to mainstream it in a lot of the work led by UN agencies and other international development agencies and donors. About five years ago, there were barely any discussions about disability issues by the government. But today, it is common to hear disability issues raised in parliament. An MP recently raised the issue of school inaccessibility and requested the Ministry of Education to work on retrofitting school structures and ensure that all new construction work follows accessibility guidelines. DPOs have also been crucial in raising the profile of disability rights. Still, there is also increasing pressure from the international community (donors) to build a more inclusive society where we can all enjoy the same rights and equal opportunities. Now the question remains: are we willing to put enough money (in terms of resources equity) where our mouths are?

## Appendix B

### Journal Entry: Doing Development and Research in the Global South

November 2, 2022

A personal response to Shaun Grech's video, "The grounded academic: Disability, poverty, and health care-action research in rural Guatemala," posted on YouTube by Integra Malta.

In this [video](#), Shaun Grech discusses conducting grounded academic research in rural Guatemala to improve disabled people's access to health care and why it is essential for researchers to conduct action research. I found his passion admirable and felt that he cared about the community where he worked. Grech is a white English man doing ethnographic work in the global South, which raises concerns, rightly so, about his intent because of the history of colonialism, racism, and uneven power relations between the North and South. He writes about his positionality and demonstrates the need for reflexivity by researchers and academics from the global North. In order to decolonize their work, researchers from the global North need to remain aware of the legacy of colonialism, be actively engaged in the decolonial process, and form equal partnerships with scholars from the global South.

In the video, he describes his work as activist in nature and not missionary work. This distinction is important because disabled people do not need experts to come and tell them how to conduct their lives and change. However, co-partnerships through action research— working together as equals (disabled people and researchers) to make the healthcare system more fair and accessible are welcome. The goal of research should be to eliminate or reduce barriers and not to create more barriers. Furthermore, research should be liberatory. This requires working together with disabled people to define the problem (felt needs and priorities), design the study methodology, and agree on each component of the study as co-researchers. Who understands the

impact of living in extreme poverty while disabled more than disabled people living in these conditions? Who understands failing to get access to medical care because it is unaffordable and inaccessible more than a disabled woman or man who has never visited a health center even though they feel their health declining over time? Disabled people are the real experts in their own lives.

Guatemala is one of the most unequal countries in the world. Grech explains that this inequality is the lasting impact of colonialism when land was appropriated and stolen from Indigenous peoples. Oppressive, exploitative, and destructive systems of colonialism built Western empires and wealth. Therefore, we cannot talk about poverty, war, and inequality in the global South without acknowledging the role of the global North in the current state of affairs. There is still a need to redress this socioeconomic injustice, and researchers can facilitate this process by conducting action research with disabled and poor people to develop roadmaps and strategies. All people deserve dignity and access to quality education, health care, transportation, and other basic needs. Yet today, Indigenous people in Guatemala remain the poorest and continue to face discrimination based on racial inequality. Any work to redress this should empower, equip, and involve the equal participation of Indigenous people and DPOs from the grassroots level. This way, they know their rights and hold their government accountable while resisting oppression.

## Appendix C

### Journal Entry: Media Representation and Mental Health

February 10

Media representation has a significant influence on how society views and interacts with people with mental health problems. The media spreads a lot of misinformation about the symptoms, causes, and treatment of mental health problems, and this has dire consequences for individuals with mental illness. Sometime back, I came across a video clip that reported that 1 in every 4 Rwandan adults has post-traumatic stress disorder (PTSD) and 1 in every 4 Rwandan adults has depression (Partners in Health, cited by CNBC Africa, 2019). I am not surprised by the numbers. But I am shocked by how little we speak about these experiences. I feel like the only time it is okay to talk about mental health problems in public in Rwanda openly is during the commemoration period.

Most of the beliefs and misinformation about mental health, and more specifically PTSD, are spread by the media and framed by the medical or charity model of disability. Mental health stigma makes it hard for people to seek mental health care and treatment. Most media representations portray PTSD as a disorder caused by war and, in Rwanda's context— as something that only affects genocide survivors or war veterans. But this is not the whole truth. A variety of life events and conditions can cause PTSD. A friend recently told me about how isolated and stigmatized she felt by her family's reaction to her diagnosis of depression and anxiety. When she got her diagnosis and medication, her mother, also a medical professional, told her never to disclose this to anyone because they would think that she is "*umusazi*" (a mad person). "*Umusazi*" is one of the most stigmatized labels for people with mental health

challenges in Rwanda. Her mother's perceived protection of her daughter from this label by silencing her is the most common response in Rwanda.

We are told that our silence will keep us safe. Popular media, in Rwanda and internationally, perpetuate this stigma through movies, for example, that continue to portray people with mental illness (for example, the "Joker") as dangerous, unpredictable, and unable to function appropriately in society. However, silence and stigma are unacceptable. Stigma—prejudicial attitudes and discriminating behavior towards individuals with mental health problems are associated with poor recovery and vocational outcomes.

Yet, as Audre Lorde aptly put it in her speech at the Modern Language Association's Lesbian and Literature panel in 1977, "I have come to believe over and over again that what is most important to me must be spoken, made verbal and shared, even at the risk of having it bruised or misunderstood. That the speaking profits me beyond any other effect" (2016, 1:24:40). Our silence cannot protect us. Our healing as a people depends on how far we are willing to construct positive community dialogues and run social campaigns to eliminate stigma and change negative beliefs, attitudes, and stereotypes about mental health problems and disability. The first step for me has been unlearning and healing self-stigma, which I am beginning to see as I examine and engage with various media representations of disabled people in Rwanda and internationally.

## Appendix D

### Journal Entry: Building bridges through digital media (“The Kwibuka podcast”)

February 17, 2022

On April 7, 2022, it will be twenty-eight years since the 1994 Genocide of the Tutsi in Rwanda that resulted in the death of over one million people. Somehow, the trauma, wounds, and grief still feel like no time has passed. Rwanda as a nation, a people group, has been affected and forever changed by the horrors of the 1994 genocide in one way or another. Every year for the past three years, the 100 days of *Kwibuka* (to remember) have left me feeling like I did not show up fully in honor of the over one million loved ones lost. Recently, I have learned that to show up fully, I need to ease into it through personal reflection, journaling, meditation on Scripture, and praying. There is a need to start preparing for the commemoration period many months in advance so that by the time April 7th rolls around, I have a plan and clear roadmap of how I will navigate through the heaviness and communal grief.

One of the valuable things that have developed or accelerated due to the COVID-19 pandemic has been an increase in the number of digital media documentaries and stories about the genocide. One of these resources that I find helpful is “The Kwibuka Podcast,” which is available on most podcast streaming platforms. This podcast gives in-depth accounts of what happened in 100 days, highlighting key known facts about each day, counting every life lost, and honoring every precious memory. Knowledge is power, especially when it comes to healing and mental health. As the Ubuntu saying goes, “I am because we are.” Every story that I hear, no matter how gruesome and horrific, helps me to make sense of the incredible feeling of loss, pain, and sadness. Digital stories have the ability to help us process what happened one minute at a

time at an individual pace. Some days, I can only listen for five minutes before it becomes too heavy, and I have to pause and pick up another day. On other days, I can listen to an entire episode.

Healing comes in waves, and I am learning to be okay with sitting with heavy feelings when they come, knowing that they are transient— they come and go and do not define me. The media is a powerful tool that Rwandans are using to share stories (including disability caused by the genocide), which is a necessary ingredient for individual and collective healing, forgiveness, renewal, and rebuilding of our nation post-genocide. I can grieve in a safe space as I create new neural pathways in my brain to heal and learn new information. I can do this because this podcast provides accurate information and stories about the genocide. As one of the memorial and life-affirming songs goes, “twibuke twiyubaka!”

**Appendix E**

**Journal Entry: Poetry and Digital Media Bridges**

**March 3, 2022**

later that night  
i held an atlas in my lap  
ran my fingers across the whole world  
and whispered  
where does it hurt?  
it answered  
everywhere  
everywhere  
everywhere. (Shire, 2015)

I love the above excerpt of the poem “what they did yesterday afternoon” by Warsan Shire (2015) so much. She is a Somali British writer and poet born in Nairobi and raised in London. Her work highlights and explores the voices and experiences of displaced people and refugees—especially African womanhood. I came across her work on social media many years ago, and I think it was on Tumblr. In this particular poem, I appreciate how it speaks about the darkness and sorrow experienced at an individual level and the pain and hurt we see everywhere. For our mental health, it is imperative that we name the hurt. Sometimes, this means reciting a poem or singing a song during a dark and bewildering time. It is essential to acknowledge our pain. Feelings come and go.

Our bodies always try to shed the stress and pain and force us to listen even when we deny our humanity. PTSD, for instance, is the body’s natural response to exposure to trauma or

an overwhelming and life-threatening event. With PTSD, specific triggers can cause one to repeatedly relive past traumatic events through flashbacks, nightmares, and hallucinations. It is like living in a loop where certain places and people take one back to a particularly traumatic moment. Some of the symptoms include being hyper-alert, irritability, anxiety and panic attacks, and sleep deprivation. Despite popular belief, PTSD is caused by a variety of situations (not just war as is commonly depicted in movies) and experiences, including childhood neglect and sexual abuse, among others. PTSD can be treated or worsen over time if left untreated. Poetry and music can be tools for healing. We begin to heal when we accept that pain is part of the full spectrum of the human experience. We cannot know joy if we do not allow ourselves to process sorrow.