

Contents

<i>List of Tables</i>	ix
<i>Acknowledgements</i>	x
Introduction	1
1. Disability: A Sociopolitical Construct	6
The Functional Limitation Model of Disability	7
Naming and Resisting Oppression: The Emergence of the Social Model	10
Disabling Barriers and the Social Construction of Disability	12
Disability in the Arts, the Media and in Daily Life: The Images That Surround Me	16
Concluding Comments	21
2. Sexuality, Disability and Women's Lived Experience	27
Women with Disabilities and their Bodies: Culture, Flesh, and Lived Experience	29
Girls with Disabilities: Messages, Perceptions and Experiences	35
Relationships, Intimacy and Well-being for Women with Disabilities	41
Concluding Comments	50
3. Reproductive Choice and Motherhood in the Context of Physical Disability	52
Women with Disabilities and Reproductive Choice	53
Parental Disability and the Well-Being of Children	61
Mothering with a Disability: Women's Lived Experience	68
Concluding Comments	79
4. The Research Process	81
Research Paradigm	82
Conducting the Research	93
Methodological Reflections	100
5. Growing Up as a Girl With a Disability	106
It's a Girl...And She Has a Disability: What Does the Future Hold?	107
Psychosexual Development: Messages, Perceptions, and Experiences	112

Social Development: Relationships with Disabled and Non-disabled Peers	118
Fighting for Self-Determination: Narratives of Risk and Survival	123
Concluding Comments	128
6. To Have Or Not To Have: Motherhood, Disability, and Choice	130
Messages and Perceptions about Sexuality and Motherhood	131
To Have or Not to Have: Weighing the Options	135
Exploring Life With and Without Children: Separating Motherhood from Female Identity	144
Concluding Comments	150
7. A Ramp to Mothering	152
The Very Beginning	153
Negotiating Roles Within the Family: Informal Support Systems	163
A Ramp to Mothering: Formal Support Systems	171
Concluding Comments	178
8. Promoting Our Children's Wellness	181
Promoting Growth and Enhancing Well-being in Children	181
The Challenge of Setting Boundaries and Managing Children's Behavior	186
Relationship With Children	190
Concluding Comments	197
9. Conclusions: Striving For Wellness	200
Resilience and Wellness Promotion for People with Disabilities	201
Girls with Disabilities: Risks, Protective Factors, and Possible Interventions	206
Women Who Are Not Mothers: Risks, Protective Factors, and Possible Interventions	213
Mothers with Disabilities and Their Families: Risks, Protective Factors, and Possible Interventions	219
Concluding Comments	226
<i>References</i>	229
<i>Index</i>	243

Introduction

It was a bitterly cold winter morning in Winnipeg, the sort of morning you want to stay in a nice cosy bed. Of all days, my husband Isaac had an early morning meeting at work and could not take three-and-a-half year old Matan to pre-school. I would have to take him on my way to work. There was only one child to be dropped off and the pre-school was immediately next to our home. However, this seemingly simple task was not easy for me as a disabled mother. There was no parking right next to the building so I decided to walk Matan to pre-school and then come back for my car.

Matan was somewhat fussy that morning; young children have a special talent for taking their time when they sense parental pressure to hurry. We left later than we should have, I walked faster than I should have and promptly found myself on a cold, snow-covered ground. For a moment, I felt a mixture of irritation and concern. I was irritated with my husband who had to leave early, and with my young son who took his time. Befittingly, my knee-jerk reaction was: "We should have left earlier". However, Matan's question of "Is it my fault, mommy?" quickly dissipated my irritation. I assured him that he was in no way responsible and that we would find a solution. I was still on the ground, however, unable to get up unassisted. Concern took over. It was -25°C and there was no one in sight. Several cars past by; however, I doubted that they could see us behind the colossal snow banks that separated the sidewalk from the road. Matan extended his little arm: "I'll help you get up, mommy". I explained as best I could under the circumstances, that he is not strong enough to lift me up; only an adult can do that. I felt the chilling wind and noticed that Matan's face was getting red from the cold. Doing my best to stay calm, I told him to walk to the building and ask someone to come and help me. He

took several steps forward and then backtracked. "But the door is too heavy for me, I won't be able to get it open". He was on the verge of tears; I did my best to reassure him as I considered my next step.

Another few cars passed by and the two of us waived at them frantically. I breathed a big sigh of relief when I noticed a car slowing down. I was further relieved when I saw a woman getting out; I always feel more comfortable getting this type of assistance from women. I still remember the petite and cheerful teacher who lifted me to my feet. I was impressed that a woman so small could be so powerful. We thanked her and ever so carefully, walked to the school. We came in, got Matan out of his boots and snowsuit and into the class. His teacher was very sympathetic and helped me comfort my clearly distressed child.

Along with my concern for Matan, I started to think about the meeting at work that I would undoubtedly be late for. I was a clinician in the school system and on that morning, had arranged to meet with a parent and with the school. The mother was highly reluctant to come to the school. It took some convincing on my part to get her to agree to the meeting. I had assured her that I would be there. I phoned the school to inform them that I would be late and slowly, carefully, walked to my car. Luckily, I had an extra set of car keys in my wallet, as my key holder was buried somewhere under a pile of snow. When I arrived at work, I was relieved to hear that the mother called to say that she would be late. After phoning the preschool to hear how Matan was doing, I sat down in the staff room for a cup of coffee. Finally, I had a few moments to think about the impact that this experience had on me. I could not deny that it had left me shaken.

Safely at home at the end of the day, Matan and I told dad what had happened. The distress no longer there, Matan was nonetheless bothered by the incident. "But I didn't help you up," he kept repeating. I sat him on my lap and explained that he did the best he could. Following my instructions as well as he did was the best help he could have provided. A little later, Matan came up to me with some of his little toy cars. He wanted to play what had happened. "One car goes by, and doesn't stop. Another car goes by and doesn't stop. Another car goes by and stops". He demonstrated with his cars as he spoke. Going along with his game, I said: "This must be the nice lady who came to help us". Matan raised his head from his cars and looked up at me with his big brown eyes. "No mommy, this is me when I'm big. I get out of the car and help you up".

This is a cherished story in our family, one that continues to move us despite the 13 years since the incident has taken place. Much has happened in our lives since that cold wintery day some 13 years ago. Matan is now 16 years old and taller than both his parents. He has since had many opportunities to fulfill his childhood dream of helping mommy up. In fact, I now fall rather frequently at home where I do not use my power wheelchair, and Matan lifts me to my feet gently and with ease. My husband Isaac has published a number of books and his academic positions have taken us to different places; I've completed a doctorate in counselling psychology and have worked as a practitioner and an academic; there have been changes in jobs, schools, even continents.

In addition to typical transitions that families go through, we are also responding to the progressive nature of my disability and to the need to continuously modify certain tasks and routines. Life isn't always easy and some days the disability is more of an issue for me than other days. Notwithstanding these challenges, I continuously strive for meaning, fulfilment, and a sense of well-being. For the most part, I am successful. I have a loving family, meaningful friendships and a fulfilling career that enables me to integrate my knowledge and experience of disability into my teaching and writing. I live in a disability-friendly house a block from Campus and am able to zoom with my power wheelchair from home to office to class. The combination of fulfilling relationships, meaningful work and near-optimal living and working conditions allow me to have a life that is deeply satisfying despite its hardships. I am aware that many of my disabled brothers and sisters face greater challenges in their quest for self-determination and control over their lives.

Being a mother is an important part of my identity and I'm forever grateful that I was able, together with my husband, to exercise the choice to have a child. It is not a decision that we made lightly; raising a child is a challenge for all parents and mothering with a disability has its added complexities. Nonetheless, raising Matan continues to enrich our lives even as we are less than two years away from the transition to College. The caring and compassion he demonstrated in early childhood has been a defining feature of who Matan is as a person.

This book is about the intersection of motherhood and physical disability. It is based on a study that explored the lived experience of women with physical disabilities, those who are mothers as well as those who are not mothers. It is couched within a social model understanding of disability that increasingly emphasizes the social,

cultural, political, and economic determinants of lived experience (Gill, Kewman & Brannon, 2003). The study attempts to answer some of the following questions: What meaning does motherhood have for women who have physical disabilities? What is it like for them? What messages do they receive about themselves as women, with or without children? What barriers do they foresee and/or come across? How do they see their future in relation to motherhood? Utilizing a combination of in-depth interviews and focus groups, I explored these and other mothering-related issues from the vantage point of disabled women with and without children.

As I indicated above, this research stems from my own lived experience, and as such, it is personally meaningful and significant. However, choosing it as my area of inquiry goes beyond a personal interest and a search for meaning. It is based on my belief that it can contribute to women participating in the research, to other women with physical disabilities, and to knowledge in the areas of disability and motherhood. The intersection of these two entities, motherhood and disability, has received little attention from the academic community. Despite technological advancements and an ethos of diversity, disabled women are rarely thought of as mothers or in conjunction with motherhood. The rich discourse on motherhood, including that which is explicitly feminist, has not traditionally included women with disabilities. It is this space that is created between motherhood and disability that I wished to explore; it is the invisibility of these women that I wished to examine and interrupt; it is their (our) stories and dreams that I wished to present. My decision to include women with and without children in the study emanated from my belief that women who do not have children also have issues regarding motherhood, issues that need to be heard and explored. I see this as fundamentally important for women with physical disabilities who live in a society that often regards motherhood as synonymous with womanhood and counter-indicated with disability.

Although I included women with and without children in the study, I chose to be specific about the types of disabilities that would be represented. The study is thus limited to women with physical disabilities who have varying levels of mobility/limb impairment. Most of the participants are wheelchair users. At least seven different types of disabilities are represented in the study. Among them are Muscular Dystrophy, Cerebral Palsy, Spinal Cord Injury, Spina Bifida and Multiple Sclerosis. My reason for limiting the sample to women with physical disabilities is based on my belief that the particular issues and

barriers they face in relation to motherhood may be inherently different from those faced by women with developmental or psychiatric disabilities. Whereas individuals with intellectual and physical impairments share some common experiences of discrimination, this should not obscure important distinctions that may be of relevance to policy and practice.

The book specifically explores the intersection of motherhood and physical disability and reviews literature that is specific to physical impairment. The importance of researching the lives of differently disabled women notwithstanding, I believe that lumping them together in one research study cannot do justice to either group. Nonetheless, I acknowledge that the book can be criticized for its focus on women with physical disabilities, women that typically participate in this type of research. As Carole Gill has noted, “a lot of research has relied on samples of those of us who are most visible: white heterosexual women with physical disabilities who are functioning in the world and who can speak or write without difficulty” (Gill, 1996a, p. 14). I admit that this description applies to my group of participants. It is my hope that future studies will focus on women with other types of disabilities and on the braiding of gender with other constructs of identity.

Index

- ableist, 16, 18, 59
- abortion, 53–69, 154, 192, 222
- abuse, 37, 38, 46, 115
- abusive, 9, 38, 45, 128, 194
- accessibility, 13, 78, 120, 186, 193, 205
- accessible, 11, 67, 72, 78, 155, 193, 208, 221, 226
- activity of daily living, 13, 20, 69
- ADA, 11, 13
- adolescence, 36, 39, 109, 112–3, 116, 123, 131, 135
- adoption, 70, 140
- adversity, 200, 203
- advocacy, 49, 72, 91, 178, 182, 210, 213, 219
- aging, 18
- American minority model, 7
- appearance, 6, 15, 29, 33, 117
 - cultural prescriptions, 32
 - deviation from norms, 32
- asexual, 32, 36, 55, 133
- assistance, 141–142
 - self-care, 16, 37, 141, 198
- assistants, 117–8, 163, 166, 174–78, 190, 219–23
- assistive technology, 68
- attendants, 37, 74, 126–7, 141–2, 156, 164, 166, 177–8, 180, 184, 211, 221
- attitudinal barriers, 19, 37, 43, 47, 59, 75, 122, 155, 199, 205
 - see also* barriers
- autobiographical accounts, 7, 68
- autonomy, 7, 10, 16, 40, 212
- barriers, 4, 10, 12, 27, 59, 75
 - architectural, 205
 - attitudinal, 19, 47, 59, 122, 155, 205
 - community access, 72
 - education, 27
 - employment, 72
 - environmental, 10
 - eradication of, 47
 - internal, 43, 44
 - oppressive, 24, 28, 33, 53–5, 74, 87, 92, 100, 106, 126, 129–30, 144, 202, 207–8, 213
 - participation, 11, 19, 20, 33
 - preventable, 9
 - psychological, 24, 50
 - recreation, 72
 - relationship, 46
 - social, 6, 11, 18, 34, 202
 - socially constructed, 23, 34, 60, 76
 - structural, 19, 24
 - subtle, 12
 - systemic, 10
- bereavement, 18
- biological, 26
- bodies, 7, 24, 28, 30–7, 40, 50, 114, 117
 - female and disabled, 28
 - of real women, 31
- bodily
 - abnormality, 8
 - experience, 30, 33
 - exposure, 37
 - representation, 33
 - struggles, 14, 24
 - suffering, 32
 - weakness, 33
- body, 19, 29
 - alienation from, 117
 - control over, 136
 - devalued, 14
 - exposure of, 37
 - failure to control, 30
 - ideals, 30
 - image, 8, 29, 31, 37, 39
 - ownership of, 38, 116, 124
- breast-feed, 222
- British
 - social model of disability, 3, 7, 10–2, 22–5, 33–4

- British – *continued*
 social modelists, 12
 survey and the health care system,
 73
- career, 3, 18, 29, 143, 145, 166, 216
 care-giving, 139–141
 care-taking and nurturing, 42
 caring, 3
 Center for Independent Living, 77, 225
 cerebral palsy, 4, 66
 child custody, 74
 child protection workers, 222
 childless women, 53–4, 57, 96, 130,
 135–6, 143–51
 children with disabilities, 36, 38–9,
 61–3, 108, 110, 118–9, 125, 128,
 129, 208, 212–13
 chronic illness, 9, 21
 civil rights, 22
 class, 28
 coalitions, 10
 cognitive functioning, 16
 collective action, 225
 collective identity, 33
 community, 8
 compassion, 3
 competence, 202–4
 competencies, 210–1
 conscientization, 22, 211
 constructivist approaches, 33
 consumer groups, 95, 225–6
 coping mechanism, 67–8
 corrective surgery, 31
 cosmetic normality, 14
 cosmetic, 15, 31
 counseling, 62, 63, 102
 critical approaches to disability
 theory, 12, 23, 25, 64–6, 81
 cultural messages, 30–1
 cultural representation, 16, 19, 20, 30,
 32
 cure, 8, 11
- deaf, 14
 death, 14, 18
 denial, 8, 13
 dependence, 8, 16, 17, 19, 25, 40, 41,
 66, 74–5, 109–10, 184, 207–9
- depression, 8, 33, 185
 dieting, 31
 dignity, 16, 38
 disabilities, 13, 25, 28, 87
 early onset, 35
 images of people with, 16, 19, 30,
 129, 198
 sociopolitical analysis of, 21
 disability, 9, 18, 33
 activists, 7, 10–1, 18
 adjustment to, 8–9, 62, 66–7, 107,
 119, 121, 141
 definition, 23, 26
 discourse, 17, 32, 62, 66, 122,
 198
 discrimination, 17–8, 28, 33, 40, 58,
 81–2, 152, 203–4
 genetic factors, 137–8
 paradigm shift, 25, 81, 89, 92, 94
 rehabilitation, 8–16, 22–6, 56, 92–3,
 218
 rights movement, 7, 23, 27, 87
 sense of self, 108
 tragedy model, 6, 11, 25
- disabled
 body, 31–2
 children, 17, 36, 62
 feminists, 27–8, 30, 33–4, 61
 girls, 61
 people’s movement, 28
- discrimination, 5, 9, 10, 12, 18, 28,
 33, 203, 216
- diversity, 4, 7, 18, 79
- domestic violence, 204
- eating disorders, 31
 economic status, 29
 education, 29, 36, 69, 212
 emotional well-being, 41
 employment, 12–3, 19, 46
 empowerment, 6, 10, 15, 22, 28, 77,
 89, 202, 204
 eugenics, 58, 154
 exclusion, 10, 21, 33, 35
- facial scaring, 32
 family, 27, 67
 dynamics, 29, 107, 123, 128
 effects on, 63

- income, 71
 - support, 15
- fashion, 31, 40
- fatigue, 14
- fear of rejection, 44
- female bodies, 30
 - see also* body
- female, 28
 - identity, 216
 - sexuality, 218
- feminism, 28
- feminist, 4, 7, 20, 32, 88
 - approach, 82–93
 - discourse, 33, 53–55
 - movement, 27, 56
 - organizations, 226
 - research, 88, 98
 - therapy, 103
- formal support, 160, 171–74, 177–80, 190, 198, 216, 222, 224
- friendships, 3, 18, 121, 212, 218
- functional limitation model, 6
- functional mobility, 9, 15
- funded assistance, 141, 164, 117, 180, 222–4, 226
- gender, 5, 18, 28, 112
- genetic disease, 61
- girls
 - able-bodied, 35
 - dating, 40
 - interventions, 211–3
 - peer rejection, 209
 - risks and protective factor, 206–13
 - sexuality, 40, 206
 - with disabilities, 36–7
- government assistance, 12, 71
- grass-roots organizations, 217
- grieving, 8
- handicap, 9
- health care coverage, 13, 58, 72
- health care professionals, 37, 67, 127, 134–5, 153–161, 216, 218, 222
- health care system, 37, 39, 73–4
- higher education, 13
- homemakers, 161, 220, 222, 225
- human genome project, 58
- iatrogenic, 10, 209
- identity, 3, 17, 20, 28, 144–6
- illness, 9, 14, 18, 21, 33, 63–4, 67, 73, 75, 77, 150, 169, 203
- images, 16–19
- impairment, 9, 15, 18, 23–5, 29, 32
- income, 69
- independent living movement, 10, 213
- informal support, 166–70, 177–81, 190, 198–99, 205, 222, 224
- institutions, 8, 12, 14, 107, 110, 123, 126
- insurance, 13, 20
- intellectual impairment, 11, 17
- interdependence, 41
- internalized
 - anger, 9
 - oppression, 45, 123
- intimacy, 17–8, 32, 36–7, 41, 112, 132–3, 213
- justice, 5
- legislation, 13
- lived experience, 4, 7, 9, 21–7, 79
- loss, 10
- macro level, 29, 210
 - changes, 213
 - interventions, 218
 - protective factor, 217–8, 224
 - risk factor, 217, 223
- male gaze, 6, 31, 117
- marginalization, 6, 10, 21, 27, 40, 87, 146, 202, 211, 213, 227
- maternity, 158–160, 222
- media, 16–7, 30
- medical
 - model, 6, 8, 13, 110, 197, 201
 - sociology, 23
- meso level, 209, 216
 - protective factors, 216, 222
 - risk factors, 222
 - service organizations, 225
 - strategies, 218
- messages, 112, 145–6, 212
 - about motherhood, 133–5
 - about sexuality, 113

- micro level, 206, 212
 - protective factors, 209, 216, 222
 - risk factors, 213, 219
 - strength, 225
- minority group model, 10
- mobility, 4, 15, 20, 29, 49, 70, 76, 96–7, 102, 136, 138
- models of disability, 6–7, 9, 30, 49, 123
- multiple sclerosis, 4
- muscular dystrophy, 4, 30

- negative biases, 44, 63

- objectification, 31
- occupational therapist, 77, 222
- oppression, 9–12, 22–4, 28, 33, 44–5, 82, 116, 123, 128–9, 207–8, 211
- oppressive, 74
 - attitudes, 33, 126, 138
 - conditions, 202
 - contexts, 28, 83
 - factors, 10, 83, 87, 106, 128, 208
 - ideologies, 224
 - practices, 205, 212
 - societal norms, 216

- paradigm, 25, 26
- parental competence, 65, 160, 202–7
- passivity, 6
- paternalistic attitudes, 9
- patriarchal society, 28, 42, 53
- peer
 - relations, 35, 39, 50, 106, 116, 118, 123
 - devaluation, 117
- perceived
 - incapacity, 8
 - inferiority, 45
- personal assistance, 43, 71
- personal tragedy model, 6, 34
- physical
 - access, 12, 13
 - appearance, 6, 15, 29–33, 40, 117
 - impairments, 5, 11, 16, 30
- physicians, 222
- physiotherapist, 20
- PND, 59–61

- poverty, 11, 13, 19, 65–6, 83, 199, 203
- powerlessness, 11, 124, 136, 212
- pregnancy, 7, 25, 73, 136–8, 153–160, 219, 222
 - messages about, 135
 - reactions to, 153–160
 - risk to fetus, 137–8, 154–5
- prejudice, 7, 15, 25, 58, 78, 90, 203, 204
- prenatal
 - diagnosis, 59
 - testing, 58–9, 61, 154
- privacy, 14, 37, 40, 114–8, 128, 206–7, 209, 213
- professional
 - assistance, 8
 - attitudes, 65
 - control, 7, 11
- progressive disability, 22
- pronatalism, 55
- protective factors, 66, 201, 203–5, 210–1
- psychiatric disabilities, 5
- psychological, 8
 - maladjustment, 8
 - research, 25
 - well-being, 21, 203
- psychosocial adaptation, 9
- puberty, 37
- public world, 13–4, 34

- quality of life, 7, 15, 25

- race, 18, 28
- ramps, 12–3
- rehabilitation, 8, 10–1, 15, 22–3
 - centers, 218
 - process, 9
 - program, 14
 - research, 92
- relationship, 27, 32, 70, 169
- reproduction, 27–8, 55, 130, 142–4, 148–50
- reproductive
 - choice, 58–9, 69, 77, 133–35, 149, 218–9
 - decision, 77
 - freedom, 55, 213

- health, 216
- options, 216, 218
- rights, 56–7
- self determination, 216, 218
- research, 4, 20, 22, 96
 - and ideology, 91
 - disability rights perspective, 83–93
 - feminist, 101
 - implications, 63
 - importance of context, 86
 - post-positivism, 84
 - relationship with participants, 88, 101–2
 - transformative, 92
- residential setting, 114, 117, 122
- resilience, 201–4, 227
- resource, 9, 28, 76, 223
- risk factors, 20, 21, 26, 50, 57, 66, 201, 203–5, 210–1, 213, 216
- role model, 110, 112, 123–4, 129, 134, 144, 206, 209, 213
- romantic, 32, 40

- school, 111, 115, 211–2
- scooter, 15, 20
- segregated settings, 115, 211–2
- selective abortion, 61
- self
 - advocacy, 78, 224–5
 - care, 20, 37
 - concept, 18, 118
 - determination, 22, 123–9, 136, 148, 209, 211, 218
 - efficacy, 109–10, 126, 203, 211
 - esteem, 18, 31, 33, 35, 37, 39, 41, 43–4, 40–50, 117, 126
 - sense of, 6, 28, 35, 39
 - sensory and mobility impairments, 13
 - separation and individuation, 39
 - service
 - needs, 72
 - providers, 37, 212
 - sexual
 - abuse, 37 *see also* abuse
 - expression, 32
 - identity, 37, 128, 209, 212
 - intimacy, 37
 - invalidation, 131–132
 - objectification, 28, 128
 - orientation, 18–28
 - rejection, 116–7, 132–3
- sexuality, 18, 28–9, 36, 39, 49, 216
 - and disability, 36
 - and reproductive health, 56
 - exploration of, 35
 - inadequate information on, 114
- social
 - action, 226
 - barriers, 6, 2, 33–41
 - change, 27, 60
 - construction of disability, 15
 - constructions of the body, 30
 - devaluation, 27, 32
 - development, 18, 106, 116, 118
 - disadvantage, 13
 - encounters, 19
 - environments, 39
 - integration, 122
 - interactions, 32
 - isolation, 39, 212
 - justice, 32, 93, 227–8
 - model of disability, 3, 11, 22–4, 33–4, 223
 - norms, 223
 - oppression, 11–2, 23
 - participation, 20
 - policies, 206, 223
 - safety net, 203, 204
 - security income, 12
 - services, 74, 205
 - stigma, 32
 - system modification, 202, 204–6
- society, 4, 11
- special education, 14, 22
- spina bifida, 4
- spinal cord injury, 4, 66
- spouses, 222
- stereotypes, 15, 19, 20–1
- strength-based orientation, 67
- strengths, 76
- support, 67, 71, 74, 209, 212
- systematic
 - barriers, 10, 122
 - exclusion, 6, 9
- thriving, 67
- Through the Looking Glass, 68, 77
- tubal ligation, 216

unemployment, 12–3

value systems, 9

violations of privacy, 128, 212

violence, 203

wheelchair, 15, 20, 25

white privilege, 10

womanhood, 4, 18

World Health Organization, 9, 201

young careers, 63, 65–6