

No BodyMind Left Behind:

Disability Justice, Biopsychosocial Model, Family Mental Health, and Recommendations

by

Ryan James Yellowlees

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APPROVED BY

Danelle Kabush, PhD, RCC, Capstone Supervisor, Master of Counselling Faculty

Jacqueline Walters, PhD, RSW, MSW Faculty Reader, Master of Counselling Faculty

School of Health and Social Sciences

Abstract

The BodyMind Capstone Project focusses on the lack of mental health supports to individuals with illnesses and/or (dis)abilities and their families, and how clinicians can improve their approaches using (dis)ability justice activism. The example of the personal narrative of the author highlights how, without intervention recognizing the biopsychosocial components of the individual experiencing illness and/or (dis)ability and their family, reveals themes of loss, grief, and other forms of trauma, often occurring over the lifespan. The capstone project utilizes critical (dis)ability theory and the biopsychosocial model lens to describe and analyse the literature. The literature review section explores key themes related to biopsychosocial model and the theoretical approaches connected to the intersectionality related to the individual living with illnesses and/or (dis)abilities, their families, community, and society. Discussions and conclusions sections involve the challenges and implications individuals with illness and/or (dis)ability and their family, along with the layers of the systems of community and society. Recommendations to providing meaningful public mental health supports to individuals and their families argues for the implementation at the individual, family, community, and societal levels leading towards meaningful awareness of (dis)ability justice and its efforts to reduce oppression.

Keywords: (dis)ability justice, illness, (dis)ability, family, biopsychosocial model, mental health interventions, health care, Canadian (dis)ability history

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Table of Contents

Abstract	2
Acknowledgements	3
Chapter 1: Introduction	6
Self-Positional Statement.....	6
(Dis)ability Justice in Context	7
Impacts of Health Condition and/or (Dis)ability	10
Defining the Biopsychosocial Model.....	11
Psychiatry Pathologizing Illness and/or (Dis)ability	11
Illness and/or (Dis)ability and MAiD	13
Capstone Project Outline	14
Chapter 2: Literature Review.....	15
Canadian (Dis)ability History	15
Defining (Dis)ability	20
Perspectives.....	22
Critical (Dis)ability Theory.....	22
The Biopsychosocial Model	23
Biopsychosocial Themes of (Dis)ability and/or Illness	23
Biological Component	23
Sociological Component.....	27
Psychological Component	32
Anticipatory Grief.....	36
Mental Health Family Interventions and Models	38
Biobehavioral Family Model	38

	5
NO BODYMIND LEFT BEHIND	Ryan Yellowlees
Family Systems-Illness Model.....	40
Mastering Each New Direction (MEND) Program	43
Other Considerations for Chronic Illness Family Interventions	47
Chapter 3: Discussion and Conclusions.....	48
Recommendations.....	49
The Impacts of Social Isolation	49
Impacts on Family Relationships.....	51
Recommendations for Society	55
Recommendations for Clinical Practice.....	58
Public Health Applications	63
Final Reflection: Living Legacy of (Dis)ability Justice	65
Conclusion	66
References.....	68

Chapter 1: Introduction

Self-Positional Statement

When a baby is born into a family, the primary hope is that the baby is born healthy. As the infant grows, the family provides for the child's development. However, with a diagnosis of Duchenne muscular dystrophy (DMD), at the age of two and a half, my family received very different news. At that time there was no chronic illness family support services available. A complete lack of psychosocial supports at the time of my diagnosis led to a lifetime of personal and family challenges. My immediate family encountered numerous negative comments, from language that involved my imminent death at an early age, to anticipating that the entire family unit would break down because of my diagnosis. My family experienced a lack of compassion from the medical community and the social worker predicted that the rest of my life would be the equivalent of a disaster. Other than a few kindly comments from the general practitioner, my family was left to fend for themselves. Consequently, the family received a terminal prognosis about my condition and that there was no need for therapeutic interventions. At the age of eight and while at an appointment to visit the neuro-muscular clinic, the neurologist informed me that I was going to die at 19-years-old from pulmonary edema, or heart failure, or would aspirate on food or water. As my mother sat there beside me trying to take in this information, I instinctively felt that what the neurologist was saying was wrong and I knew in that moment that I developed what became this capstone project: the separation of the body/mind for individuals with illness and/or (dis)ability. In only treating the mental or physical health aspects of an illness and/or (dis)ability, the person experiences unnecessary suffering by not being treated as a whole person. Even though I did not have the language or the concept of justice at eight-years-old, I

instinctively engaged in my own interpretation of injustice; that an adult was attempting to devalue me because I have a health diagnosis.

(Dis)ability Justice in Context

Within helping professions, social justice focusses on working towards promoting an equitable society that includes everyone and responds to each person's needs (Oxford Reference, 2021; Dictionary.com, 2021). (Dis)ability justice advocates search out a “framework for liberation that seeks to end ableism in connection with ending all other forms of oppression” (ADJC, 2021, para. 6). Both social and (dis)ability justice focus on critically examining current (dis)ability studies, research, and movements dedicated to improving the lives of people with diverse lived experiences and more specifically, those who have health conditions and/or (dis)abilities. Based on my lived experience, along with a developing understanding of how society engages with individuals with illness and/or (dis)abilities, the historical contexts, along with the emerging critical (dis)ability theories into social justice and (dis)ability justice. This capstone project will scrutinize the historical, political, and cultural aspects of how individuals living with illness and/or (dis)ability and their families navigate their lives. To better support individuals and families on a practical level, this capstone project proposes that there needs to be more awareness, better counsellor training, promotion of programs that implement (dis)ability justice approaches.

Within civil societies, people state that all citizens are born equal and deserve fair treatment, that they have inalienable rights, particularly for those born with or who acquire conditions that require support. Further, humans have rights that recognize the "equitable distribution of resources among members of a community" (Dictionary.com, 2021, para. 1), so that, "their rights are recognized and protected, and decisions are made in ways that are fair and

honest" (Oxford Reference, 2021, para. 1). Authors, such as Susan Wendell, a (dis)ability activist, and her non-fiction book, *The Rejected Body*, 1996, details the politics of individual's illness and/or (dis)ability and how society regards death as a topic to be avoided at all costs. Wendell's honest examination of illness and/or (dis)ability, demonstrates how most people fear illness and death. According to Esther Ingham, PhD in counselling psychology and as a (dis)ability activist, in their 2018 article, *Attitudes Towards Disability in Society Viewed Through the Lens of Critical Disability Theory: An Analysis of Me Before You*, suggests how society's view of (dis)ability reinforces negative psychological concepts regarding a person's lived experience in a world that ostracizes individuals with (dis)abilities and health conditions (Ingham, 2018a). They note how society reinforces the negative perceptions of individuals experiencing illness and/or (dis)ability. As Ingham notes, within a social model of (dis)ability, the social environment causes (dis)abilities, not people who are born with or who acquire a health condition. Ingham further condemns many of the institutions, including medical and psychological ones that persist in minimizing their clients' experiences as they navigate living with illness and/or (dis)ability (Ingham, 2018a). Ingham suggests that, while most may not recognize the reality of vulnerability and consequently may experience (dis)ability themselves, they persist in ablest behaviours and patterns that reject and fundamentally discriminate (Ingham, 2018a). Ingham notes a focus on, "medical and tragedy models. The medical model privileges and presumes able bodies to be the desired norm, and (dis)ability as something to be pathologised" (Ingham, 2018a, p. 5). Like what occurred in my family over the years, Ingham highlights how having a particular physical or cognitive lived (dis)ability experience is somehow, "brave, beautiful or special just for living" (Ingham, 2018a, p. 5).

Further to the context of what society rejects as outside of their belief system of what is healthy and not-(dis)abled, advocates of (dis)ability justice reinforce that society could embrace a more equitable approach. Berne et al. indicate in their article, what they term, *10 Principles of Disability Justice*, as a form of ethics in (dis)ability justice. Berne et al. address the concept that we all have core value, regardless of our lived experiences (Berne et al., 2018). Further, they argue that everything within us and surrounding us is all interconnected (Berne et al., 2018), which we recognize as the concept of intersectionality. And, finally, Berne et al. advocate for what they term as, “Collective Liberation”, which adopts all intersectionality's of the human condition (Berne et al., 2018), and “where no body/mind is left behind” (Berne et al., 2018, p. 229).

Medical Context of Illness and/or (Dis)ability

In many societies, the typical response to health concerns is to separate the body from the mind. Health care practitioners are trained to focus on the physical aspects of health and when their patients living with illness and/or (dis)ability attempt to engage their physicians with mental health concerns they are often left to cope on their own. Along with pre-existing physical health needs, those living with illness and/or (dis)ability are at a particular disadvantage in their quality of life needs as there persists in a lack of mental health services associated with the medical health care environment. According to Andrews et al, (2021), individuals, when diagnosed with a life-threatening or health condition and/or (dis)ability, encounter a plethora of challenges within the existing health care system. These include aspects associated with physical, psychological, and societal determinants related to one’s quantity and quality of life and the aspects of ableism that increase the stressors connected to a person’s health state (Andrews et al., 2021). Thus, an entire family is often at risk for mental health deterioration.

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Impacts of Health Condition and/or (Dis)ability

As far back as 1987, Rolland, in their article, *Family Illness Paradigms: Evolution and Significance*, indicated that for those individuals diagnosed with a chronic medical condition likely follow a slow, progressive path deemed nonfatal, fluctuating, interspersed with elements of remission, then relapse, which all contribute to family exhaustion (Rolland, 1987). In their more recent 2018 book, *Helping Couples and Families Navigate Illness and Disability*, Rolland describes the impact on families and primary caregivers encountering a family member's health status as all-encompassing shifts in family relationships and dynamics, financial constraints, or worse, and limited access to timely, meaningful health services (Rolland, 2018). In a 2017 survey, *Canadian Survey on Disability: A Demographic, Employment and Income Profile of Canadians with Disabilities Aged 15 Years and Over, 2017*, authors Morris et al., reveal that within Canada, as of 2017, "one in five (22%) aged 15 years and over – or about 6.2 million individuals had one or more disabilities" (Morris et al., 2018, p. 4). Subsequently, too, is the reality that there an increasing number of Canadians who have or will acquire or develop a progressive condition resulting in (dis)ability. Based on evidence gathered over the past 35 years, the negative affects to individuals and families reinforces the societal narrative that to be born with or acquire a life-long condition requiring medical, sociological, or psychological supports, result in higher rates of early mortality and poor mental health outcomes compounded by living in poverty and experiencing abuses in all forms. In a 2018 Statistics Canada analysis, *Juristat: Violent Victimization of Women with Disabilities, 2014*, author Cotter, indicates that for individuals diagnosed with mental health concerns such as anxiety or depression, they experience at least four times the rate of violent victimization (Cotter, 2018), than members of Canadian society not identified with a (dis)ability. Tragically, these individuals encountered

some form of physical or sexual abuse during their childhoods and of the reported data, only, "four in ten (40%) indicate the abuse they suffered" (Cotter, 2018, p. 3). For women with (dis)abilities, the risks for abuse in all forms is at least, "two times higher when compared to those without a disability" (Cotter, 2018, p. 3), reflecting how the impacts of the lack of mental health services for families and individuals with health conditions and/or (dis)abilities. Based on statistics indicating the harms perpetrated against individuals experiencing (dis)ability, the need to develop and implement models of holistic health practices such as the biopsychosocial model become essential to the person, their family, their community, and society.

Defining the Biopsychosocial Model

Critical disability theory and the biopsychosocial model offer links between a social model of (dis)ability, while acknowledging the biological, psychological, and sociological components of each. To mitigate the harms leading to abuse due to a lack of mental health supports, the concept of integrating a holistic model of health aims to address health inequities. University of Rochester's, Doctors Engel, and Romano, credited with developing the biopsychosocial model emphasising on the "importance of understanding human health and illness in their fullest contexts" (University of Rochester, 2022, p. 1). Included within the biopsychosocial approach are, "social factors and their complex interactions in understanding health, illness, and health care delivery" (University of Rochester, 2022, p. 1), which focus on each person's individual aspects of their physical, psychological, and social experiences and interactions.

Psychiatry Pathologizing Illness and/or (Dis)ability

While the biopsychosocial model utilizes a holistic view of health, medical and psychiatric practitioners use the American Psychiatric Association's *Diagnostic and Statistical*

Manual, 5th edition, 2013 (DSM-5) to diagnose psychiatric disorders. The primary concern of relying on the DSM-5 is its tendency to regard a person as a set of symptoms, further dehumanizing them. For example, a person living with (dis)ability and/or illness who may be experiencing anxiety related to a new set of physical concerns, could receive a psychiatric diagnosis of Illness Anxiety Disorder, due to their having daily, "E. Illness preoccupation [having] been present for at least 6 months, but the specific illness that is feared may change over that period of time" (American Psychiatric Association, 2013a). Another aspect of pathologizing an individual's lived experience is to diagnose them as being a "Care-seeking type: Medical care, including physician visits or undergoing tests and procedures, is frequently used" (American Psychiatric Association, 2013a). Persons living with (dis)ability and/or illness, may be deemed pathological precisely because their "Illness becomes a central feature of the individual's identity and self-image, a frequent topic of social discourse, and a characteristic response to stressful life events" (DSM-5, 2013a). As Ingham notes, in their 2018 analysis paper, they highlight how (dis)ability follows "essentialist medical and tragedy models. The medical model privileges and presumes able bodies to be the desired norm, and disability as something to be pathologised" (Ingham, 2018a, p. 5). By following the logic of Ingham's central awareness, a person diagnosed with an immune-compromised condition such as having cancer may be diagnosed with Illness Anxiety Disorder, as outlined in the DSM-5. The DSM-5 would state that any emotional concern a person would have about their continual changes in health that last more than three months is considered a stressor that reoccurs or persists, and that this stressor is also pathological (American Psychiatric Association, 2013). One of the most challenging descriptors in the DSM-5 details the idea of comorbidity in which there "may be the major psychological response to a medical disorder" (American Psychiatric Association, 2013b), which, in a person's lived

experience further attempts to negate them to a collection of symptoms that reduce their existence to a pathology.

Illness and/or (Dis)ability and MAiD

Further to the concept that individuals living with illness and/or (dis)ability may be regarded as a collection of symptoms requiring treatment and/or cure, the lack of meaningful mental health supports adds to their poor health. In Downie and Schuklenk's 2021 article, *Social Determinants of Health and Slippery Slopes in Assisted Dying Debates: Lessons from Canada*, they investigate Canada's 2016 legalization of MAiD (Medical Assistance in Dying). The subsequent 2020-2021 debate determine if a person's natural foreseeable death need be included as an eligibility criterion (Downie & Schuklenk, 2021). However, if a person diagnosed with, "irremediable severe mental illnesses or a range of diverse, severe disabilities" (Downie & Schuklenk, 2021, p. 662), the Federal court argued about who should have access to MAiD. The debate centres around the language of "suffering" and what constitutes the degree of the person's ability to foresee the lessening of their "suffering". Consequently, doctors and psychiatrists hold enormous responsibility for their clients who they diagnose with illness and/or (dis)ability and mental illness. In the Federal government legislation, Bill C-7 2021, in which a person receiving a mental illness diagnosis is ineligible from receiving MAiD, they may be eligible for MAiD, occurring as early as March 2023 (Downie & Schuklenk, 2021), indicating the legal, medical, ethical, and moral complexities that encompass MAiD. Even more concerning regarding the legislation is that individuals with illness and/or (dis)ability may be eligible for MAiD, even if their death is not foreseeable (Downie & Schuklenk, 2021). Downie and Schuklenk reveal the argument that a person living with illness and/or (dis)ability receive societal messaging that their lives "are not worth living". The reality is that a lack of social determinants of health result in a

poorer quality of life and subsequently, drive requests for MAiD (Downie & Schuklenk, 2021). Controversies arise regarding the reasons for why a person would seek MAiD: those diagnosed with a mental illness may do so due to “poverty, homelessness, and racism”, or those who are diagnosed with a medical condition whose treatment protocols no longer available to them, or they no longer respond to the protocols, making MAiD the only viable option (Downie & Schuklenk, 2021). The authors highlight how a dearth of specialist resources or funding for mental health supports (Downie & Schuklenk, 2021), exacerbates the feelings of hopelessness and desperation these individuals face, or as Downie and Schuklenk, state as a “long-festering scandal” (Downie & Schuklenk, 2021, p. 665-66). Once we recognize that Canada’s Bill C-7 removes the naturally foreseeable death requirement, the safeguards designed to protect those persons diagnosed with (dis)abilities and/or mental illnesses, would “descend down a slippery slope to a place where persons would be coerced into MAiD” (Downie & Schuklenk, 2021, p. 667). The primary consideration for Canadian society is, how to much “suffering” a person is expected to endure before their lives become forfeit; the slippery slope could become a cliff (Downie & Schuklenk, 2021).

Even Health Canada in its 2022 report, *Final Report of the Expert Panel on MAiD and Mental Illness*, recognize individuals seeking MAiD due to financial duress and “suffering”, downplay the social determinants affecting requests for MAiD (Health Canada, 2022). Health Canada notes that the subject is “beyond the scope of this report” (Health Canada, 2022, p. 45-46), leading us to wonder if there is a potential eugenics agenda, which will be further explored in the Literature Review section.

Capstone Project Outline

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This Capstone project explores the perspectives of critical disability theory, the biopsychosocial model, Canadian (dis)ability history, and defining (dis)ability. The biopsychosocial approach to (dis)ability and illness, mental health family interventions and models, discussion, implications, and conclusion all emphasize the case for implementing a (dis)ability justice approach. One of the many aspects of this Capstone project is to define the lived experiences of individuals experiencing a chronic illness and/or (dis)ability and how these experiences affect their mental health and wellbeing. Of the research explored, Rolland, Wood, and the MEND program, see (Distelberg et al., 2014, 2016, 2020; Emerson et al., 2016a, 2016b; Rolland, 1987, 1999, 2017, 2018; Rolland and Williams, 2005; Tapanes et al., 2015; Williams-Reade et al., 2019; Wood, 1993; Wood et al., 2000, 2015), have investigated, implemented, and evaluated the benefits of integrated mental health therapeutic interventions devoted entirely to benefit individuals and families. Consequently, the Capstone project will use (dis)ability justice lenses and the biopsychosocial model to expand on the historical and current societal narratives of individuals living with illness and/or (dis)ability, how they perceive themselves in response to how they are perceived, and how counsellors can move towards a strength-based approach, which will enhance mental health family interventions for these individuals and their families.

Chapter 2: Literature Review

Canadian (Dis)ability History

Editors Hansen, Hanes, & Driedger, 2018, in the first-ever published Canadian disability history textbook, *Untold Stories: A Canadian Disability History Reader*, reveal in Hanes' chapter, *Service Clubs and the Emergence of Societies for Crippled Children in Canada: The Rise of the Ontario Society for Crippled Children, 1920–1940*, they describe how,

“Critical disability theory and histories of disabilities inform us that disability is a socially constructed category wherein disability definitions, paradigms, models, and theories are shaped and molded according to historical time, place, culture, and political economy, as well as societal values and beliefs” (Hanes, 2018, p. 140).

There is a long history in Canada of portraying individuals living with a health condition and/or (dis)ability, especially children, as a form of charity who must be regarded as a gift to be pitied but without basic human rights (Hanes, 2018). While there have been efforts to distance disability as a charity, there remains a strong connection between the ability to campaign for fundraising for medical services using a narrative of human suffering. One non-profit organization, Variety Club, known as the “Children’s Charity”, hosts an annual televised event where musicians, artists, and former and current families promote the benefits of donating to the BC Children’s Hospital, located in Vancouver, where clients and their families receive additional services not covered by the provincial health care plan. What makes this event so popular is how the appeal to support the “cute” child “overcome” adversity drives the narrative of regarding the child as a “hero” worthy of help. However, the “cute” child grows into an adult, who may encounter emotional, physical, psychological, and sexual abuse. An extreme form of bodily violation occurred in many provinces in Canada over the past century. For example, in Malacrida, 2018, *Work, Education, and Privilege: An Alberta City’s Parasitical Relationship to Its Total Institution for “Mental Defectives”*, in a subsequent chapter, describes how the province in the mid-1930’s, amended their eugenics’ program for sexual sterilization so that consent was not needed (Malacrida, 2018). For individuals considered “mentally defective”, their rights as humans were violated primarily due to a lack of “volunteers” for Alberta’s campaign of ridding the province of people judged to be “less than” (Malacrida, 2018). In Turcotte’s chapter,

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in *Untold Stories: A Canadian Disability History Reader*, they reveal how “lawyers, politicians, and everyday people in Alberta got to the point where they believed it possible, and, in fact, rightful, to treat disability as a social evil and to seek to remove its existence through sterilization” (Turcotte, 2018, p. 179). Turcotte’s chapter explores Canada’s criminal actions of performing surgeries as a form of eugenics better associated with Nazi Germany. However, the reality is that the Nazis acquired and perfected their “Nazi extermination programs—eugenics and the concept of creating a “master race”—was popular here in North America long before it was implemented en masse” (Turcotte, 2018, p. 180). Concepts in the early 20th century that, “our society could be made better by sterilizing marginalized groups, such as persons living with disabilities, immigrants, or Indigenous peoples” (Turcotte, 2018, p. 180), cemented ideas that individuals who are deemed “other” or “subhuman” have no business existing and certainly no business pro-creating another generation. Provinces such as Alberta where no consent was needed, and in BC where “consent” was required, does not change the attitudes that persist for decades into the 21st century where deeper analyses are needed to, “include how eugenics may still inform both social consciousness and public policy today” (Turcotte, 2018, p. 181). Turcotte further damns academia that deny the sterilization programs conducted in Canadian society in the past promoted a, “particular construction of disability as “evil” and the sterilization programs that sought to prevent the recurrence of disability were an attempt to exterminate a particular social group from the Canadian population” (Turcotte, 2018, p. 186). When we recognize that funding for academic research arrives via governments, using phrases such as “genocide” to describe what occurred to people with disabilities who experienced trauma from being sterilized against their will, we persist in a charity/medical model narrative that de-personifies the person, leading to bullying, discrimination, and acts of hatred. Conversely, by promoting, “able-

bodiedness, or not living with a disability” (Turcotte, 2018, p. 186), they indicate that the ideology of eugenics persists, in which core beliefs indicate that “whole” bodies are “normal”, while illness and/or (dis)ability is “unnatural” or undesirable in comparison with able-bodiedness (Turcotte, 2018). Within mainstream Canadian society, there persists a notion that illness and/or (dis)ability is a social threat that needs to have policies to intervene in reproduction or biopsychosocial supports (Turcotte, 2018). As unpalatable the notion of modern-day eugenics may be to any woman contemplating pregnancy, the “re-emergence of eugenic ideologies [occurs] within discussions of genetic testing and emerging reproductive technologies” (Turcotte, 2018, pp. 192-93). For example, women are coerced into believing that society associates illness and/or (dis)ability as a challenge to what is “normal” within our ableist societies and physical environments that cause (dis)ability (Turcotte, 2018). We also know this type of societal assumptions as a social model of (dis)ability. Turcotte’s condemnation of the furthering of damning females to lives of guilt and shame should they pursue having children that society deems as “healthy”, meaning “perfect”, reinforces our ableist beliefs. Utilizing an integrated health care approach could reduce the stigma and shame that women face when they give birth to children experiencing health conditions and/or (dis)ability.

Along with society’s treatment of women during their childbearing years, Wolbring and Ball’s chapter, *History of Science and Technology and Canadians with Disabilities*, explore how women in Canada from the 1900s to the 1970s encountered surgical procedures such as coerced or forced sterilization, various genetic testing that resulted in linked abortions being performed, to in vitro fertilization of the fetus to determine genetic viability, and all are linked to pursuing eugenics (Wolbring & Ball, 2018). The authors argue that there is a lack of discussion from medical practitioners regarding practices related to genetic testing and supports, abortion, and the

ethics surrounding eugenics (Wolbring & Ball, 2018). If doctors hold to subjective attitudes regarding the moral high ground of human existence, they may also hold to negative perceptions about the value of each human's worth in society. The long-held views of medical professionals regarding societal acceptance or rejection of each person based on their inherent worth in society ebbs and flows with each generation. As Driedger notes in their chapter, *Organizing for Change: The Origins and History of the Manitoba League of the Physically Handicapped, 1967–1982*, they describe how medical and “public attitudes” (Driedger, 2018, p. 223), continually inaccurately portray people with illness and/or (dis)abilities, resulting in their feeling helpless (Driedger, 2018). Worse, they note, is how there is an unhealthy dichotomy that pits individuals with (dis)ability, the various terms, and designations of (dis)ability, and the dogmatic persistence of those engaged in ableism, leading to an imbalance between whose rights are protected and upheld (Driedger, 2018). This “othering” of people with disabilities persists in all areas of life, including the notion that, as Galer, in their chapter, *Building an Accessible House of Labour: Work, Disability Rights, and the Canadian Labour Movement*, suggest that regarding illness and/or (dis)ability is some kind of “affliction” that affects individuals who brought about their own suffering (Galer, 2018). This concept is problematic for society as they cling to these socially constructed barriers of what it means to be “typical” due to able-bodiedness (Galer, 2018). McGillivray, in the final chapter of *Untold Stories: A Canadian Disability History Reader*, *Living in the Midst: Re-imagining Disability through Auto/biography*, reinforces how limited our society is in accepting an individual living with illness and/or (dis)ability, how society continually tries to “cure” or “overcome” their lived experiences (McGillivray, 2018). The tendency is to “reduce” the person to a collection of symptoms as they struggle with their own fears and anxieties related to their health condition precisely because they have an illness

and/or (dis)ability (McGillivray, 2018). By dehumanizing another person, we may reinforce the dissociation that “others” are not worthy of our attention and care in relation to their having an illness and/or (dis)ability. McGillivray reinforces the “discourses of separation, disconnection, and Otherness; these discourses isolate, marginalize, categorize, medicalize, segregate, hierarchize, and oppress” (McGillivray, 2018, p. 359). McGillivray notes that all human beings have or will have a (dis)ability, and by denying this reality, we also deny our humanity, and consequently, the opportunities to experience all the fulsomeness of our existence (McGillivray, 2018).

Defining (Dis)ability

To better understand the concept or idea of (dis)ability we need to locate and provide definitions that reflect a mirror of our existence because gazing at our reflections reminds us of our mortality and eventual (dis)ablement. The recognition that we, as humans, all encounter states of vulnerability, from birth onwards, that even our existence is pre-destined to go extinct, creates a state of dissonance for theorists. With the awareness that at any point in our lives we may become or acquire illness and/or (dis)ability, we can shift our thinking that reflects a more inclusive definition of (dis)ability. If we adopt and accept that (dis)ability is a social system, based on a hierarchy of power and is on a continuum, we can recognize, as Schalk describes in the 2017 article, *Critical Disability Studies as Methodology*, the concept that people are not (dis)abled, but their physical and social environments create (dis)abilities much as humans label according to race or gender (Schalk, 2017). Schalk suggests that using “(dis)ability as a term for a system of power that shapes bodymind norms and expectations allows for the inclusion of illness and disease” (Schalk, 2017, p. 2). And, Ingham, highlights how society’s negative

perception regarding (dis)ability has profound psychological harms to the person affected due to a lack of full inclusion into society (Ingham, 2018a). As Susan Wendell states in their book, “‘disability’ to refer to any lack of ability to perform activities that is either necessary for survival or to participate in some major aspect of life in society” (Wendell, 1996, p. 23). They remind us that,

“Social constructionist analyses of disability, in which oppressive institutions and policies, prejudiced attitudes, discrimination, cultural misrepresentation, and other social injustices are seen as the primary causes of disability, can reduce attention to those disabled people whose bodies are highly medicalized because of their suffering, their deteriorating health, or the threat of death. Moreover, some unhealthy disabled people, as well as some healthy people with disabilities, experience physical or psychological burdens that no amount of social justice can eliminate” (Wendell, 2013, p. 162).

As mentioned previously, the recognition of the biopsychosocial approach, as developed by Drs. George Engel and John Romano, involves concepts and constructs that recognize that all aspects of the quality of the human life must include the biological, psychological, and sociological as vital to human health (University of Rochester, 2022). Berne et al., offer several ways in which society could regard (dis)ability from a (dis)ability justice approach. For example, Principle 5, “Recognizing Wholeness [:] people have inherent worth outside of capitalist notions of productivity. Each person has an internal experience composed of their own thoughts, sensations, emotions, fantasies, perceptions, and idiosyncrasies” (Berne et al., 2018, p. 2), reinforcing that regardless of (dis)ability, the individual can have an expansive experience of life. As well, in Principle 7, “Commitment to Cross-Disability Solidarity [:] [the authors] break down ableist/patriarchal/racist/classed isolation between people as isolation ultimately undermines

collective liberation” (Berne et al., 2018, p. 2), reminding us that without (dis)ability justice, no one person is truly free.

Perspectives

At some point in our lives, we may directly or indirectly encounter or experience (dis)ability and/or illness, either as an infant, child, or adult. While individually, we may be capable of self-administering of health care, generally, we rely on our families, our communities and society to support us when we are in need. Medically, societies have a social safety net in which to provide health care; however, communities, families, and individuals struggle to access the psychological and social services that maintain mental health and well-being. Without implementing a holistic approach such as the biopsychosocial model, individuals, families, communities, and society encounter needless grief, loss, and suffering. This Capstone project will use a critical (dis)ability theory lens and the biopsychosocial model to expand on the (dis)ability justice agenda and could be used to argue for the need to implement integrated health care for individuals and families affected by health conditions and/or (dis)abilities.

Critical (Dis)ability Theory

Critical disability theory consists of several approaches as outlined in the Stanford Encyclopedia of Philosophy, 2019, to “analyze disability as a cultural, historical, relative, social, and political phenomenon” (Stanford Encyclopedia of Philosophy, 2019, para. 1). According to Dictionary.com, ableism is defined as the “tendency to regard people with a disability as incomplete, diminished, or damaged, and to measure the quality of life with a disability against a nondisabled standard” (Dictionary.com, para. 2, 2022). Further, “critical theory identifies, describes, and analyzes the subsumed or hidden origins of social and political culture, discourses, and institutions” (Stanford Encyclopedia of Philosophy, 2019, para. 12). A core aspect of critical

(dis)ability theory is dedicated “toward exposing and analyzing ableism” (Stanford Encyclopedia of Philosophy, 2019, para. 18), which, to (dis)ability advocates, represents a perspective seldom acknowledged in mainstream societies. Minich, in their excellent 2016 article, “*Enabling Whom? Critical Disability Studies Now*”, examines social norms and conditions related to defining and, consequently, stigmatizing individuals living with illness and/or (dis)ability (Minich, 2016). Minich’s definition, focusses not only defining critical (dis)ability theory, but also analysing and critiquing the language used within a writing style (Minich, 2016).

The Biopsychosocial Model

According to the University of Rochester Medical Center’s, Drs. George Engel and John Romano, developed the concept model of understanding how the biological, psychological, and sociological intersect to mutually influence physical and mental health, and how integrated health services may be delivered, resulting in the creation of the biopsychosocial approach/model (University of Rochester, 2022).

Biopsychosocial Themes of (Dis)ability and/or Illness

Biological Component

When examining the literature related to the biological aspects of the biopsychosocial approach of (dis)ability and/or illness, several subthemes emerge related, but not limited to abnormal, biomedical, chronic illness, cure, defective, diagnosis, disease, dysfunction, eugenics, fatal, health condition, illness, lifesaving, life-threatening, MAiD, maladaptive, medical model, pathology, prevention, progressive, or terminal. Of these, the medicalizing of individuals lands under the overarching descriptor of pathologizing them as a collection of symptoms, rather than as a person who has agency towards their lived experience. As Susan Wendell argues, “neither impairment nor disability can be defined purely in biomedical terms” (Wendell, 1996, p. 35).

They further state that, “Scientific medicine participates in and fosters the myth of control by focussing on cures and lifesaving medical interventions, and by neglect[ing] chronic illnesses” (Wendell, 1996, p. 94). Instead, the medical model of (dis)ability focusses on, describing the person as a collection of physical conditions and symptoms (Wendell, 1996), which serves to depersonify the person. Ingham reminds us in their article, that the essential narrative consists of a person being a medical tragedy that will continue to suffer in body/mind until they die precisely because they have acquired or live with a (dis)ability (Ingham, 2018a). Further, Ingham argues that the standard Westernized medical model “privileges and presumes able bodies to be the desired norm, and disability as something to be pathologized” (Ingham, 2018a, p. 5). Frustratingly, Ingham notes, medical practitioners tend to promote a diagnosis with rehabilitation and/or cure as the primary goal of treatment norms that unintentionally dehumanizes the person, ignoring their choices or opportunities to realize a quality of life (Ingham, 2018a).

For individuals diagnosed with a (dis)ability, Wendell, in their 2013 chapter from the book titled, *The Disability Studies Reader*, chapter, *Unhealthy Disabled: Treating Chronic Illnesses as Disabilities*, proposes that people with illness and/or (dis)abilities create new narratives to their health conditions to describe their medical diagnosis and their lived experiences (Wendell, 2013). They also suggest that when they are acknowledged for these lived experiences individuals experiencing health conditions reinforce how we are all valuable for who we are as human beings who engage with body and mind (Wendell, 2013). However, Wendell is highly critical of how society tends to promote risky or even harmful “cures” as a means of reducing or eliminating illness and/or (dis)ability. However, individuals experiencing health concerns and/or (dis)abilities continue to live in poverty, unable to access even the most fundamental supports and services that could improve their lives (Wendell, 2013). And Wendell

reinforces however the language changes towards engaging in eugenics policies and practices, the result remains the same, to eradicate health conditions and/or (dis)abilities, namely, to prevent the birth and existence of those who present as “abnormal” (Wendell, 2013).

Biologically-speaking, individuals diagnosed with chronic or acquired illness encounter significant challenges accessing medical care pre-COVID-19 and during the pandemic, these inequities increased. Guidry-Grimes et al., 2020, reveal in their essay, *Disability Rights as a Necessary Framework for Crisis Standards of Care and the Future of Health Care*, how there remains a persistent form of discrimination towards individuals with health conditions and/or (dis)abilities trying to access healthcare (Guidry-Grimes et al., 2020). Globally, all societies have experienced extraordinary demands on their health care systems and in the Global North countries. Even with exceptional medical resources, their most vulnerable populations endured in many cases, the very worst outcomes, including death related to but not necessarily from COVID-19. Andrews et al., in their 2021 article, *No Body is Expendable: Medical Rationing and Disability Justice During the COVID-19 Pandemic*, report how those within the (dis)ability communities encountered disparities within the entire health care environment, from access to personal protective equipment, to receiving timely assessments, to maintaining basic health care needs (Andrews et al., 2021). Many health care systems resorted to using a form of triage policies in relation to determining who, ultimately would live and who would die, based on their diagnosis and level of supports required, often using the QOL (quality of life) measures to justify their decision-making (Andrews et al., 2021).

The idea that members of society are deemed “expendable” reinforces a long-standing dilemma faced by society when medical or other forms of crises emerge; that is, the tendency towards labelling and condemning those often the most vulnerable being those living with illness

and/or (dis)ability (Andrews et al., 2021). Implied in their article is the notion that health care professionals base their decisions on how who is more likely to survive (Andrews et al., 2021). As Andrews et al. remind us, humans are fully capable of performing acts of ableism to improve the chances of another's survival (Andrews et al., 2021). Andrews et al., also note how there remains a disconnect when individuals with illness and/or (dis)abilities who self-identify as having a quality of life [QOL], encounter health care practitioners who do not believe their claims about living a "good life". These opposing perspectives further deny and diminish a person's positive life experiences and accomplishments (Andrews et al., 2021). The authors remind us of the notion that, too often, those deemed as "outsiders" persist on a negative emphasis on the illness and/or (dis)ability (Andrews et al., 2021). As well, the concept of "medical rationing" is a constant in today's health care environments when resources are stretched to capacity, and Andrews et al., recognize how each medical department must carefully determine the risks of costs and benefits in every situation, often with the rationalizing that persons living with illness and/or (dis)abilities are considered expendable when faced with extraordinary need (Andrews et al., 2021). Fundamentally, "healthy" people are biased towards people who are not. And, as Andrews et al., state, "not providing resources to a particular individual, in other words allowing them to die, has an emotional toll on health care providers as well, now identified in the trauma literature as moral injury" (Andrews et al., 2021, p. 454), perpetuating ableism. Once we call out ableism for what it is, the primary purpose is to hold control or power over those who live with chronic health and/or (dis)ability, negating their lived experiences, their hopes, and, at times, their lives (Andrews et al., 2021). As Andrews et al., reinforce, because of their implied power over those persons who need to access their services,

there remains a persistent holding of negative attitudes, especially for those persons who experience chronic health conditions or other forms of (dis)ability (Andrews et al., 2021).

Sociological Component

In 2022, as society persists in stereotyping individuals experiencing chronic illness and/or (dis)ability, how they approach the conundrum of BodyMind within the biopsychosocial model remains a significant challenge. Disability activist, academic, and artist, Liz Crow in their 1996 article, *Including All of Our Lives: Renewing the Social Model of Disability*, provides an analysis of society's sociological construction of (dis)ability, as (dis)abling social environments, attitudes, prejudice, and stereotypes that emphasize an individual's perceived inability rather than ability (Crow, 1996). They describe how having a (dis)ability is the equivalent of being deemed not worth existing (Crow, 1996). Crow, as a person living with (dis)ability argues, that regardless of society's persistence in the language and construct of the medical model of (dis)ability, many individuals with (dis)ability deny their lived experiences (Crow, 1996). They state, "Impairment is safer not mentioned at all" (Crow, 1996, pp. 4-5). As Crow indicated in their article, a kind of silence by omission may mean the difference between receiving health care or being denied as they are deemed too complex and taking up too many resources needed for others (Crow, 1996). They remind us, too similarly of those facing "post-COVID-19 syndrome" in 2022 and beyond, of those who "remain frustrated and disheartened by pain, fatigue, depression and chronic illness" (Crow, 1996, pp. 4-5). Crow contends that, "many of us fear for our futures with progressive or additional impairments; we are afraid we may die early or that suicide may seem our only option; we desperately seek some effective medical intervention" (Crow, 1996, pp. 4-5).

Susan Wendell describes how society's assumptions and expectations tend to focus on a dichotomy between having a health condition, or being "healthy" and "normal", versus being

(dis)abled and “unhealthy” or “abnormal” (Wendell, 1996). They further remind us about how both biology and sociology become complicit in the intersectionality between the two constructs (Wendell, 1996). As much as we can recognize and engage in the work towards integrating our biological and sociological selves, we must acknowledge that we cannot remove all suffering and that all conditions cannot be cured, fixed, or engineered away (Wendell, 1996). Almost 20 years later, Wendell reinforces how,

“Social constructionist analyses of disability, in which oppressive institutions and policies, prejudiced attitudes, discrimination, cultural misrepresentation, and other social injustices are seen as the primary causes of disability, can reduce attention to those disabled people whose bodies are highly medicalized because of their suffering, their deteriorating health, or the threat of death. Moreover, some unhealthy disabled people, as well as some healthy people with disabilities, experience physical or psychological burdens that no amount of social justice can eliminate” (Wendell, 2013, p. 162).

Ingham, too, in their 2018 article, posits that our denial culture and tendency towards blaming those who do acquire an illness and/or other form of physical (dis)ability (Ingham, 2018a). They evoke a discomfort to those deemed able-bodied, who are constantly reminded of those forced to live in an ableist environment that negates and discriminates against the person (Ingham, 2018a). Using social media to describe the state of those living with (dis)abilities, the tendency is towards language such as, “brave, beautiful or special just for living [and] is a condescending portrayal from an able-bodied perspective that locates the purpose of existence for disabled people as one to make able-bodied others feel better about themselves” (Ingham, 2018a, p. 5). Many of Ingham’s observations suggest a tone of bitterness towards well-meaning community members who tend towards a labelling of anyone who presents differently to

themselves. The risk with this type of thinking is how isolating perceived difference may encourage resentment, jealousy, and hatred when attention is made towards the individual living with illness and/or (dis)ability. By calling out these forms of expressions, Ingham and other (dis)ability activists remind us that, as humans, we all have behaviours and characteristics that do not conform to society's standards or norms.

The degree to which able-bodied individuals and societies perpetrate the “special” narrative shows up on every level of medical literature, academic scholarship, and popular culture. In Jeffrey Preston's, 2017, textbook, *The Fantasy of Disability: Images of Loss in Popular Culture*, they note how health practitioners constantly describe a person living with a health condition and/or (dis)ability as somehow “less than” precisely because they must rely on diagnoses and symptoms and the subsequent resources to exist (Preston, 2017). They observe how, having a difference in their physical person is considered a diversion of what is “normal”. Preston argues that for those in positions of power, particularly within the medical community, a person is considered medically deviant, which represents weakness and dependence on others, again to exist (Preston, 2017). Further, they indicate that any form of (dis)ability, particularly in physical and social environments, prevents individuals from engaging fully in their lives (Preston, 2017). Preston has little empathy, even sympathy, for the medical profession that, “validate society's fantasy that life with a disability is a condition that should be overcome” (Preston, 2017, p. 6). When practitioners are given the kind of power that determines the outcome of a person's life, not only the quantity but the quality, we need to be more cognizant that people in the medical profession do not have “an advanced understanding of life and the ways of the world” (Preston, 2017, p. 6). Dr. Preston, as a person living with a (dis)ability, admonishes their audience, “Rather than speaking to the lived experience of disability, portrayals

of disability in the media are reminiscent of confrontations with the nondisabled, dubbed here “normates,” (Preston, 2017, p. 6). For these “normates”, Preston’s (dis)ability is deemed a tragedy of epic characteristics (Preston, 2017). The uncomfortable reminder that, “we are all vulnerable and, perhaps, that to be human is to be disabled” (Preston, 2017, p. 10), persists as a tragic narrative. From a sociological perspective, Preston’s use of a wheelchair is a symbol that represents the most feared object in human society, that of vulnerability and death and therefore, must be avoided at all costs (Preston, 2017).

Along with Preston’s damning statements about society’s fears of illness and/or (dis)ability, Minich notes that within healthcare cultures, people who do not identify as having a (dis)ability, have an unspoken idea that each person is responsible for their own self-care and that society is not culpable nor morally responsible for their care (Minich, 2016). Minich is highly critical of how research tends to focus on removing the subjectivity of individual’s lived experiences, instead using objective methods to analyse the person, only regarded as an object of deterioration and early death, furthering adding to discrimination and stigma (Minich, 2016). They assert that, “disability is often used rhetorically to reinforce white supremacy” (Minich, 2016 p. 3), as though only those hold power, usually “privileged, healthy, white males”, which encourages patriarchy and consequently reinforces eugenics rhetoric.

Schalk agrees with Minich when they note how those engaged in so-called critical (dis)ability studies tends to emphasize the scientific approach, negating the person or people they are meant to “study” (Schalk, 2017). Schalk recognizes that (dis)ability itself becomes a social construct based on social systems focussing on categories, ranking, valuations of all aspects of the human condition (Schalk, 2017). Their understanding of how society determines who is “able” and who is “(dis)abled” reinforces the schism in (dis)ability studies of those considered

“capable” versus “incapable”, fully immersed in power, privilege, and oppression (Schalk, 2017). By deliberately choosing, “... (dis)ability as a term for a system of power that shapes bodymind norms and expectations allows for the inclusion of illness and disease no matter what the current definitions of disability might be” (Schalk, 2017, p. 2).

Conversely, Andrews et al., in their 2021 article, detail social injustices when they report how society engages in ableism when they determine that illness and/or (dis)ability is a pathology when a person requires medical care. The tendency, once a person receives a diagnosis is to “normalize” or encourage assimilation as a means of “fitting in” with the status quo (Andrews et al., 2021). Individuals living with health conditions and/or (dis)abilities requiring medical care may encounter differing barriers when accessing medical care. Health care barriers to services include, a lack of funding for medications, waitlists to receive physiotherapy services, and limited or no access to mental health supports, if at all. Andrews et al., condemns society’s inability to provide culturally competent care, which an individual’s quality and quantity of their biopsychosocial health (Andrews et al., 2021). The researchers’ core assessment is that due to ableism, a person’s quality of life is “poor” particularly as the individual has a (dis)ability, almost as though the person by virtue of their diagnosis is not fully recognized as having value to those deemed non-(dis)abled.

According to a 2021 report conducted by the Angus Reid Institute, 59% of individuals identifying with a (dis)ability “believe the current supports and benefits available to people living with disabilities are inadequate” (Angus Reid Institute, 2021, p. 1). While approximately 30% of adults describe themselves as “living with some form of disability or a health condition that poses at least some difficulty for daily activities” (Angus Reid Institute, 2021, p. 3), these numbers do not reflect children and youth, nor does this number accurately note those

individuals deemed incapable of responding to survey questions. The report illustrates that while the majority of Canadian society appears to deny the existence of illness and/or (dis)ability within their communities, the reality is that most citizens will experience even a temporary (dis)ability at some point in their lives and by continuously denying this vulnerability, we are denying our core humanity.

Tragically, Rivas et al., in their 2021 paper, *The Many Faces of Disability in Evidence for Policy and Practice: Embracing Complexity*, note that too many governments consider individuals living with (dis)ability as somehow “deviant and non-productive members of society, with the disability their individual fault [and] relegate them to the scrapheap of society” (Rivas et al., 2021, p. 192).

These forms of discrimination and stigmatization occur every day and show up, Soetemans and Jackson state, in their 2021 article, *The Influence of Accessibility on Perceptions of People with Disabilities*, as “seemingly benign expressions such as communications of pity and provision of unwanted help. Such forms of paternalism have been theorized to arise in response to social conditions that fail to highlight people’s competencies” (Soetemans & Jackson, 2021, p. 185). In their article, the authors indicate “Canadian Human Rights Commissions’ 2018 annual report listed that fifty-two percent of all violation complaints accepted by grounds of discrimination were related to disability, which is a thirty-three percent increase from the decade’s average” (Soetemans & Jackson, 2021, pp. 186-87). Based on the numbers from the 2018 annual report and currently, from a potential post-pandemic or endemic world, we can assume that people living with illness and/or (dis)abilities are and will continue to encounter core discrimination and oppression for their mere existence.

Psychological Component

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From the dire reports, surveys, and personal stories of individuals and their families where chronic illness and (dis)ability are present, the conclusion reached is one of psychological harm. As Ingham reminds us, this type of mental health deterioration “highlight the negative psychological impact on the individual of their physical and social environment” (Ingham, 2018a, p. 4). Sociologists, psychologists, family doctors, counsellors, and other health care providers may refer to individuals with chronic illness as experiencing variations on loss, grief, or multiple variations of these core psychological experiences. Robinson, in their 2016, paper, *Trust, Health Care Relationships, and Chronic Illness: A Theoretical Coalescence*, indicate an historical focus on the type, quality, and quantity of health care relationships occurring between the person, their family members and healthcare providers and other clinicians (Robinson, 2016). From the author’s perspective there must be accurate and reflective research that recognizes the core impacts of these health care relationships, from a biological as well as a psychological perspective (Robinson, 2016). An individual’s lived experience along with that of their family members belong with the entire realm of the chronic illness narrative (Robinson, 2016). There is also an awareness that individuals experiencing chronic illness along with their family members, are impacted by the illness and/or (dis)ability as the burden of care and responsibility falls to those immediate family members, shaping how care is provided (Robinson, 2016). While health care provisions primarily fall to family members who constantly engage with multiple care providers, their level of trust depends on how responsive the rest of the community and society is to their needs (Robinson, 2016). Worse, individuals and their family members are often left to fend for themselves in carving out “a good life” as there remains a misalignment with society’s tendency to perform crisis management while ignoring a long-term vision of care (Robinson, 2016). The key message from individuals and families concerns how to establish and maintain a

level of trust towards clinicians and other healthcare providers that reflects their loved ones needs; in other words, to be acknowledged, heard, and respected (Robinson, 2016).

Similarly, Ingham, in their 2018 article, *The (Physically) Wounded Healer: The Impact of a Physical Disability on Training and Development as a Counselling Psychologist: A Case Study*, they share the diverse nature of (dis)ability and how clinicians must engage in a therapeutic relationship based on these personal connections (Ingham, 2018b). Ingham reminds us that without recognizing the benefits of establishing and maintaining a respectful, biopsychosocial relationship with individuals living with chronic health and/or (dis)ability, we risk increasing the range of harmful human emotions. We can know the profound stages of another's dying process yet be completely unaware of the presence of a continuum of grief and loss for a person with a (dis)ability and/or their illness.

As Harris and Winokuer state in their 2019 textbook, *Principles and Practice of Grief Counseling* (3rd ed.), “grief is a process that enables us to rebuild our assumptive world after it has been broken, and losses that are both death and nondeath-related can assault our assumptions about how the world should work” (Harris & Winokuer, 2019, p. 121). They describe various forms of losses, ranging from what we recognize as mild disappointment occurring during a typical day, to a diagnosis of chronic fatigue syndrome, to developing post-COVID-19 syndrome, and much more severe diagnoses including terminal forms of cancer, and sudden losses related to accidents, and other forms of trauma. Harris and Winokuer investigate the terminology and descriptions of the numerous conditions of loss, including ambiguous loss, living loss, nonfinite loss, and chronic sorrow. For example, during ambiguous loss, as suggested, the loss is “unclear, cannot be fixed, and has no closure. It can be physical or psychological” (Harris & Winokuer, 2019, p. 135). Interestingly, during a phase of ambiguous

loss, the person “may be psychologically present but physically absent or in losses in which an individual may be physically present but psychologically absent” (Harris & Winokuer, 2019, p. 135). For those experiencing living losses, there persists the concept that those who “live” with their losses, they also continue to exist even as they continue to experience the sensation of loss, a kind of dissociation between body and mind (Harris & Winokuer, 2019). For too many people, their loss experiences “that are enduring in nature, usually precipitated by a negative life event or an episode that retains a physical and/or psychological presence in an ongoing manner” (Harris & Winokuer, 2019, p. 135). While the concept of nonfinite loss is ambivalent in nature, continuous with constant changes or frames of reference, the uncertainty often stays with the person for the rest of their lives (Harris & Winokuer, 2019). Finally, Harris and Winokuer describe,

“three main factors that separate nonfinite loss experiences from the experience of a death-related loss: 1. The loss (and grief) is continuous and ongoing, 2. The loss prevents normal developmental expectations from being met, and the inability to meet these expectations may be because of physical, cognitive, social, emotional, or spiritual losses” (Harris & Winokuer, 2019, pp. 124-25).

There may be present within the second set of factors that involve,

“ongoing uncertainty regarding what will happen next[;] There is often a sense of disconnection from the mainstream and what is generally viewed as “normal” in human experience[;] The magnitude of the loss is frequently unrecognized or not acknowledged by others” (Harris & Winokuer, 2019, pp. 124-25).

Tragically, those who live with chronic and progressive health conditions, they must continuously adjust and accommodate to an accumulation of losses due to the health condition while others do not acknowledge, recognize, or even deny the person's experience of loss (Harris & Winokuer, 2019). For individuals living through this form of loss, they often know when there are few-to-no supports available to assist them in their grief and losses (Harris & Winokuer, 2019). The core message that individuals receive is that they are expected to automatically adjust to the loss and "just move on" with their lives (Harris & Winokuer, 2019). Nearly everyone recognizes that life can be brutally unfair and why must we live in an environment that does not meet our expectations, and, perhaps, worse, why do we have to suffer? Harris and Winokuer recognize that humanity tends towards an assumption that life is expected to be "fair" and "predictable" and worse, that society "should" provide adequate forms of justice and compensation (Harris & Winokuer, 2019). From these forms of losses also comes chronic sorrow, which is an "ongoing response to losses that are continual and unending in nature; the chronicity of the feelings and the ongoing nature of the loss separate chronic sorrow apart from other forms of grief" (Harris & Winokuer, 2019, p. 135).

Anticipatory Grief. Along with these named forms of grief, anticipatory grief is one that not only acknowledges the psychological but also the theoretical. Overton and Cottone, in their 2016, article, *Anticipatory Grief: A Family Systems Approach*, describe this type of grief as a universal process that humans experience related to something deemed "expected", yet persists in impacting the life of the individual diagnosed with a progressive terminal illness and their family member along with their immediate community (Overton & Cottone, 2016). Overton and Cottone indicate that in times related to a person's impending death, anticipatory grief, when ignored or overlooked causes significant emotional distress when compared to the person's

actual death (Overton & Cottone, 2016). During anticipatory loss experiences, family members often persist with a family narrative that contains their feelings of the loss and becomes a core story they carry (Overton & Cottone, 2016). The authors remind us that,

“Each member of the family will anticipate and process the loss differently. Members of the family may be at various and different points of acceptance which can be difficult for the family unit. Anticipatory grief is more than post death grief stretched out. It is a journey toward the ultimate loss through a death and is composed of many losses, of the past, present, and the future” (Overton & Cottone, 2016, p. 432).

Further to Overton and Cottone’s observations about the forms and functions of anticipatory grief, Coelho and Barbosa, 2017, in their *Family Anticipatory Grief: An Integrative Literature Review*, note how the “person may recognize the family death cognitively and still maintain the fantasy that it can be avoidable” (Coelho & Barbosa, 2017, p. 780). The person or family may be in a state of grief for the loss of a future not realized, plans not occurring, any dreams or goals that will never happen, and, tragically, letting go of the idea that they will be abandoned or left behind (Coelho & Barbosa, 2017).

As well, Rogalla, in their 2020 article, *Anticipatory Grief, Proactive Coping, Social Support, and Growth: Exploring Positive Experiences of Preparing for Loss*, state that notifying a family member that their loved one is diagnosed with a terminal illness is, in, of itself, significantly distressing, which could lead to a grief reaction (Rogalla, 2020). There are two components of anticipatory grief processes: “First, notification of a loved one’s terminal illness can constitute a traumatic experience. Second, these results reemphasize that growth in the face of grief is not only an outcome but an ongoing process that can begin prior to a physical death of

a loved one” (Rogalla, 2020, p. 123). By acknowledging that anticipatory grief is real and yet is often denied, persists in an ableism narrative.

Mental Health Family Interventions and Models

The previous sections provided an overview of how an individual and their families encounter (dis)ability and/or illnesses, as well as a broader understanding of the theories that attempt to describe the lived experiences of persons with (dis)abilities and/or illnesses. The impacts on their mental health affect not only the person, but also the members of that person’s family, whether they be biological or acquired through adoption or other forms of guardianship or caregiving systems requires us to examine interventions and models to better assist these individuals and their families. By introducing these various approaches and models, from a chronological perspective, the theories offered have provided the historical context for the current approaches and future healthcare and family interventions.

Biobehavioral Family Model

Beatrice Wood developed their concept of a family model in their 1993, “*Psychosomatic Family*”: *A Biobehavioral Family Model of Pediatric Illness*, article, the notion of how the biopsychosocial factors influence health and (dis)ability (Wood, 1993). Within this proposed model, Wood suggests that there are designs representing the unique efforts each family engages to maintain a homeostatic system and how these designs interact depending on the health and/or (dis)ability of the family member (Wood, 1993). Consequently, they argue that each family may either increase or decrease their coping strategies, which we recognize as a family system (Wood, 1993). Wood presents their family systems model as a means of either improving or exacerbate the health and/or (dis)ability of the person (Wood, 1993). By expanding on the biopsychosocial model of the family’s individual and collective response to the diagnosis, health

condition, and/or (dis)ability, could determine a number of differing responses (Wood, 1993). As well, families tend to respond to the experiences of their loved one with a (dis)ability and/or illness according to their “cultural, psychological, biological, and environmental contexts” (Wood, 1993, p. 266).

By 2000, in their revised behavioural model, Wood et al., in their article, *Evolving the Biobehavioral Family Model: The Fit of Attachment*, discuss how the latest *Biobehavioral Family Model (BBFM)* incorporates the relationship between parent-child as a form of attachment, which includes biopsychosocial aspects of health (Wood et al., 2000). The quality of parent/child interactions will often determine the relationship is potentially supportive or hostile (Wood et al., 2000). When a confirmed or unconfirmed diagnosis or a change in the child’s health occurs, the ways in which family responds have both harmful or beneficial aspects to the family dynamic, and particularly on the biopsychosocial factors of health (Wood et al., 2000). From their 2015 article, *Review of Family Relational Stress and Pediatric Asthma: The Value of Biopsychosocial Systemic Models*, Wood et al., reinforce, as the title suggests, the value of the biopsychosocial model, particularly when there are “health disparities are due to multiple factors, many of which are social and emotional stressors” (Wood et al., 2015, p. 379). Wood et al., note how individuals and families encounter intense periods of extreme stressors, coupled with threatening financial changes such as one or both parents losing or leaving their careers and/or employment to care for their child, causing major changes in coping skills (Wood et al., 2015). Often, these partnerships encounter high levels of anxiety, emotional distress, reduced emotional tolerance, increased substance-use, and continual tension (Wood et al., 2015). The intensity of the family psychological environment contributes to the overall heightened emotional exchanges (Wood et al., 2015). The authors recognize too, that “Parent-child relational security is a

construct related to attachment. Insecure parent-child relations produce stress in the child or exacerbate the effect of family or external stress on the child” (Wood et al., 2015, p. 382). When there are insecure or poor child-parent-caregiver attachments or relationships, research indicates the ways in which poor family relationships further impact the child’s physiological health (Wood et al., 2015). For a child or youth experiencing illness and/or (dis)ability within the family, an important core step is to recognize the harms of stress to a child experiencing a health condition and/or (dis)ability (Wood et al., 2015). When acknowledging the impact(s) of how the child’s illness and/or (dis)ability affects families, there may be further opportunities to reduce the psychological stresses for all.

Family Systems-Illness Model

Other biopsychosocial models have emerged over the years, including those of John Rolland. They coined, in their 1987 paper, *Family Illness Paradigms: Evolution and Significance*, a “typology of illness conceptualizes broad distinctions of disease onset (acute v. gradual), course (progressive v. constant v. relapsing), outcome (fatal v. shortened life span or possible sudden death v. no effect on longevity), and incapacitation (none v. mild v. moderate v. severe)” (Rolland, 1987, p. 483). They further describe the core components of psychosocial themes of illness and (dis)ability as three phases including crisis, chronic, and terminal (Rolland, 1987). Most tellingly, for families and individuals experiencing illness and/or (dis)abilities, Rolland illustrates four elements of the “family illness belief system: 1) The family’s sense of mastery and control over the illness. 2) The family’s multigenerational evolutionary process with illness, loss, and crisis. 3) The family’s ethnic, cultural, and religious beliefs. 4) The family’s assumptions about the etiology of illness” (Rolland, 1987, p. 485). From a Westernized perspective, Rolland poses that each family view of what “health” or “healthy” will determine

how they engage (or not) with the illness and/or (dis)ability and to the health-care environment (Rolland, 1987). Rolland endorses a model that includes and interacts with society's cultures, religions, races, and/or other intersectionality's that engage with families' experiences with illness, loss, grief, or other health crisis (Rolland, 1987). Families generally regard any change as an existential threat (Rolland, 1987). A key awareness Rolland brings forward, is how the,

“psychosocial type of illness [plays out for each family]. For example, some types of diseases exert enormous strain on the family by a pileup of psychosocial demands over a short period of time. Illnesses that begin with an acute onset, are progressive, moderate to severely incapacitating, and life-threatening are most extreme in this regard” (Rolland, 1987, p. 489).

Rolland also notes how, in situations deemed less urgent, slow progression, or gradual loss of health, may also increase family fatigue (Rolland, 1987). As each family is unique in their lived experiences, particularly when or if there has been a previous illness or health event, their perceptions about what kind of and how the illness progresses determines the family's “beliefs about mastery and control” (Rolland, 1987, p. 490). Each time there is a health emergency or change in their loved one's condition will require shifting thinking about how the family will function in the near future (Rolland, 1987). Another major factor is how each family's culture, values, and even how they describe themselves as a family will determine who becomes the primary caregiver to the individual with the illness and/or (dis)ability, and what, if any other roles extended family members may or may not perform as caregivers (Rolland, 1987).

Rolland's early work into the biopsychosocial factors regarding what may have caused an individual's health condition, plays a significant role in how the family copes with the diagnosis and prognosis (Rolland, 1987). Consequently, by describing the health condition's potential

disease course from a chronology over time may assist individuals and family members to better understand the disease and/or (dis)ability process; by asking questions and sorting out answers could determine how the family system copes with the health condition and/or (dis)ability (Rolland, 1987). Rolland compares this process to the idea of another family member joining them at some later date when routines and coping strategies have already been planned or mapped out; however, each situation calls for adapting to a new set of rules or changes such new symptoms, shifts in ability, threats of loss and/or death (Rolland, 1987). Individuals and families are especially impacted if a disease and/or (dis)ability returns after a period of remission, or a new health threat is diagnosed, or the illness progresses to numerous transitions, leading to impending death (Rolland, 1987). Families, then, are constantly encountering changes that require altering their lives to modify to the disease, illness, and/or (dis)ability (Rolland, 1987). Comparisons families describe in these stages of their loved one's illness is to that of being a combat soldier, constantly on alert, aware of any possibility of health crisis.

Rolland, in their 1999 article, *Parental Illness and Disability: A Family Systems Framework*, reinforce a biopsychosocial approach, focussing on a systems perspective, with the family at the centre fully immersed within the illness and/or (dis)ability (Rolland, 1999). Further, Rolland suggests that within the Family Systems Framework, “three dimensions [exist]: (1) ‘psychosocial types’ of illness and disability; (2) major developmental phases in their natural history; and (3) key family system variables” (Rolland, 1999, p. 244). Another key awareness, Rolland notes is how chronic illness ending in death or in a diminished quality of life impacts the individual and their family in profound psychosocial ways, particularly those illnesses that have unpredictable outcomes, such as neuromuscular conditions (Rolland, 1999). Individuals and families vary in their coping skills and ability to plan for anything involving the future, often

struggling with expected anxieties and the uncertainty of their future and how much time they have left to live, both in terms of quantity and quality (Rolland, 1999). For example, families often encounter what is termed a “chronic phase [which] can be marked by constancy, progression, or episodic change. It has been referred to as ‘the long haul’” (Rolland, 1999, p. 247). However, when a person enters a terminal period, everything surrounds the person and their eventual death (Rolland, 1999). As well, family members each experience the eventuality of their loved one’s death in their own way, ranging from denial, rage, to acceptance.

What can be problematic for individuals and their family members is the deterioration of interpersonal relationships with each other become due to an intensified focus or identification with the individual’s illness and/or (dis)ability which can consume all aspects of family life and identity (Rolland, 1999). For families facing the first health and/or (dis)ability crisis, often involving the medical community and practitioners, the family may find themselves plunged into researching everything they can about their loved one’s condition (Rolland, 1999). Rolland encourages families to become as educated as early and as thoroughly as they can regarding the etiology of the health condition which may assist them in determining caregiving requirements (Rolland, 1999). Using a Family Systems Framework provides families with an alternative narratives about the individual’s illness and/or (dis)ability that may offer greater strength and ability to navigate for resources and services (Rolland, 1999).

Mastering Each New Direction (MEND) Program

Within the last decade, an interdisciplinary team of clinicians, ranging from nurses, doctors, medical specialists, counsellors, psychologists, and psychiatrists based at Loma Linda University Health, California, developed MEND, Mastering Each New Direction, a program that supports individuals and their families to maintain and/or enhance their emotional, physical,

health and well-being when facing illness or treatment (Loma Linda University Health, 2022).

The MEND team colleagues, Distelberg, Tapanes, Montgomery, and others, whose 2014 article, *Evaluation of a Family Systems Intervention for Managing Pediatric Chronic Illness: Mastering Each New Direction (MEND)*, highlights the lack of biopsychosocial interventions aimed at helping families cope with chronic illness (Distelberg et al., 2014). The authors claim that MEND not only acknowledges individuals experiencing chronic illness along with their families but offers a variety of biopsychosocial approaches that may validate and endorse their specific needs (Distelberg et al., 2014). MEND recognizes that individuals experiencing chronic illness and/or (dis)ability and their families as an interdependent system that prioritizes the individual, their family, community, and health care systems (Distelberg et al., 2014). MEND also facilitates disease management through processes aimed at the cognitive, emotional, and social approaches (Distelberg et al., 2014). One of the most interesting aspects of MEND reinforces a solid grasp of family system theories as these are understood as a complicated, interdependent relationship between disease processes, types and duration of stressors, parent-child relationships, and family intersectionality's (Distelberg et al., 2014). Another specialized feature of MEND is in how, "chronic illness places stress on the family and the child, [and] places significant focus on understanding and addressing patterns of coping and stress" (Distelberg et al., 2014, p. 196). Distelberg et al., provide meaningful goals designed to engage in stress-reducing both within the micro-and-mesosystem levels (Distelberg et al., 2014).

One example of how MEND engages children living with chronic illness and/or (dis)ability intentionally integrates them with other children experiencing chronic illness and/or (dis)ability (Distelberg et al., 2014). Another significant component of MEND allows for previous or prior participants to mentor new participants (Distelberg et al., 2014). As well,

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MEND reinforces how the mind-body connection is an interconnected process offering opportunities for the individual experiencing chronic illness and/or (dis)ability to learn how to cope with their emotional and psychological states (Distelberg et al., 2014). MEND colleagues take the time needed to familiarize themselves with each participant, learning their individual family culture, including their narratives of the chronic illness and/or (dis)ability to better understand how the family perceives meanings around the illness (Distelberg et al., 2014). By paying close attention to every family's particular illness narrative, MEND notes the context aspects unique to each individual and their family, recognizing familiar themes, developing a common language to promote change (Distelberg et al., 2014).

In a follow-up article, Tapanes et al., in their 2015, *Mastering Each New Direction (MEND): A Biopsychosocial Intervention for Pediatric Chronic Illness*, investigate MEND's success in supporting children's ability to develop interdependence regarding their treatment regimen (Tapanes et al., 2015). Results indicate that MEND programs decrease the harmful psychological effects of chronic illness and/or (dis)ability on the person and family system (Tapanes et al., 2015). MEND's primary success involves providing thorough assessments by taking to time needed to better understand the needs of each person and their family (Tapanes et al., 2015). Once these assessments are completed, goal setting offers opportunities to continue relationship-building between members of the healthcare team, along with counsellors, therapists, and other mental health professionals to develop and maintain essential sense of safety and trust (Tapanes et al., 2015). By focussing on each family system and how they function, the MEND team has a better understanding where congruity occurs and when stresses arise between family members based on their verbal and non-verbal expressions (Tapanes et al., 2015). By

the third phase of MEND, the responsibility for counsellors and other mental health practitioners is to engage in promoting ideas of making meaning towards their potential to make change in their lived experiences and how the family may support these changes (Tapanes et al., 2015). As well, the MEND team collaborates with the individual and their family members towards implementing and sustaining the change(s) identified (Tapanes et al., 2015). At the final stage of MEND, individuals living with chronic illness and/or (dis)ability and their family continue to work with the mental health team to maintain their internal strengths and resources to persist with changes that reflects their dreams and goals (Tapanes et al., 2015). One of the best aspects of the MEND program is how all participants can identify the progress they have made as individuals and as family members. Using this kind of strength-based approach offers opportunities towards “developing a new narrative in which the family begins to see the future as containing setbacks and difficulties, but with the knowledge that if they rely on their strengths they can move through future challenges” (Tapanes et al., 2015, pp. 6-7). The counsellor’s role provides for the future planning in which the individual living with chronic illness and/or (dis)ability and their family prepare for the future, regardless of the inevitable changes that will occur (Tapanes et al., 2015).

In Emerson et al., 2019 article, *Longitudinal Model Predicting Self-Concept in Pediatric Chronic Illness*, in which they evaluate MEND’s longitudinal study examining the program’s outcomes, determine that “improving family dynamics may alleviate the negative repercussions that can follow the onset of a CI [Chronic Illness] (e.g., depressive symptoms, negative self-concept, and the nonadherence to treatment that often follows)” (Emerson et al., 2019, p. 110). Conclusions indicate that MEND’s strengths include better family communication, reported feelings of wellbeing, and better treatment outcomes (Emerson et al., 2019). Along with the

Emerson et al. study, Distelberg et al., in their 2020 article, *Evaluation of the Healthcare Cost Offsets of Mend: A Family Systems Mental Health Integration Approach*, engaged in a retrospective study focussing on MEND's programming and core costs associated with chronic illness. The overall financial savings represents over one third or a "34.3% reduction in healthcare costs suggest[ing] that a family systems psychosocial intervention can offer a health system an overall cost savings" (Distelberg et al., 2020, p. 1). The core recommendations promote a fully integrated approach "where the entire care team is working in the same space and utilizing the same systems" (Distelberg et al., 2020, p. 3). As well, the MEND team "work in the same location, share space, conduct informal and formal case consultation, and communicate throughout the day-to-day care of the [clients]" (Distelberg et al., 2020, p. 5). Having an approach such as what the MEND team offers, provides individuals and family members a measure of consistency often lacking in most chronic illness situations.

Other Considerations for Chronic Illness Family Interventions

According to Forbat, in their 2020 article, *The Role and Value of Family Therapy for People Living with Cancer: A Rapid Review of Recent Evidence*, not only is there a core lack of all-encompassing supports available to individuals living with chronic illness and their families, but psychosocial supports tend to be limited as well. For example, Forbat indicates that individuals living with cancer must include psychosocial care of all members of their family (Forbat, 2020). This population have similar concerns surrounding grief, loss, death or dying and that clinicians remain unaware of their needs (Forbat, 2020). Using a whole systems approach benefits all involved, leading to systemic change, such as using emerging technologies (Forbat, 2020). Canter et al., in their 2019 article, *Technology-Focused Family Interventions in Pediatric Chronic Illness: A Systematic Review*, describe how electronic or eHealth and mHealth (mobile)

interventions could assist individuals living with chronic illness and/or (dis)abilities (Canter et al., 2019). Another advantage of utilizing electronic options allows family members to work together reducing the impacts of harmful family dynamics by engaging in their biopsychosocial functioning (Canter et al., 2019). By providing alternatives that respect the individual experiencing chronic illness and/or (dis)ability and their family members, the interventions may better support overall outcomes that extend beyond the family unit into the community and society-at-large.

Chapter 3: Discussion and Conclusions

In this Capstone project, titled, *No BodyMind Left Behind: Disability Justice, Biopsychosocial Model, Family Mental Health and Recommendations*, we critically examine how Western societies separates physical and mental health, often with drastic consequences, not only for the individual living with chronic illness and/or (dis)ability, but their immediate family members, and communities. The implications to these individuals, families, communities, and societies holds enormous ethical and moral dilemmas, as various approaches and models emerge to reflect a more strength-based narrative, one that focusses on resources every person possesses. The challenges include ableism, discrimination, oppression, and many other forms of denial of an individual's human existence, focussing on the dichotomy between a strengths-based narratives and a deficit narratives. As noted in the thesis, focussing on (dis)ability justice and the biopsychosocial model provides opportunities to accurately assess mental health in individuals experiencing chronic illness and/or (dis)ability and their families by offering interventions, such as Rolland's, FSI model, MEND program, or telehealth services. By implementing these approaches, evidence supports their efficacy not only for the person, but also to those participating in the creation, development, and evaluation of their core benefits. For example, by

including family members, the extended medical support team, mental health counsellors, and other integrated health care team members, the individual most impacted develops autonomy that shapes their sense of self-worth as a meaningful member of society.

Recommendations

The Impacts of Social Isolation

Despite improvements in access to services, individuals living with illness and/or (dis)ability and their families often remain alone, literally left to figure out next steps, from understanding what the diagnosis of their loved one's means, to attending specialist's appointments discussing what might be the prognosis. One of the less-frequently studied areas in research is the intersectionality between having a (dis)ability, experiencing loneliness and isolation, and the negative impacts brought on by events such as the global COVID-19 pandemic. In their 2021 article, *Impact of social isolation on mortality and morbidity in 20 high-income, middle-income, and low-income countries in five continents*, Naito et al., address the affects social isolation has on the quality and quantity of those living on five continents (Naito et al., 2021). Findings demonstrate higher levels of stroke, cardiovascular disease (CVD), and pneumonia, often resulting in death (Naito et al, 2021). We can infer from the research that combinations related to the determinants of health does not discriminate when it comes to the harms caused by isolation, regardless of how old a person is, what gender they are, where they live, or how much they earn, and is often exacerbated in youth and males (Naito et al, 2021). In isolation, a person may become increasingly lonely and consequently, shift their previous health practices towards a decline and offers from concerned family or friends is rebuffed or outright rejected, resulting in poor choices around increased substance use, and other self-harming behaviours (Naito et al, 2021). As well, when a person is diagnosed with a (dis)ability, their

sense of rejection within their small-town communities often escalates their sense of social isolation (Naito et al, 2021). Poor health outcomes lead to a “26% increased risk of mortality” (Naito et al, 2021, p. 7), with research reinforcing global statistics (Naito et al, 2021). The situation in Canada mirrors that of the rest of the world in reporting loneliness or feeling lonely as a major reason for their lack of health. In a 2021 survey conducted by Statistics Canada, *Canadian Social Survey: Loneliness in Canada*, one in 10 youth, 15 years of age or older indicated they generally felt lonely most of the time, while three out of 10 young people stated they felt lonely some of the time (Statistics Canada, 2021). As they age, young persons experienced more feelings of loneliness, upwards of 23% in comparison for adults ages 25 to 34 (Statistics Canada, 2021). Worryingly, nearly 50% of the Canadian population who stated they felt lonely and indicated that their mental health was fair or poor (Statistics Canada, 2021). The report connects loneliness and overall physical and mental health as significant factors due to the lack of friends, family, or others who provide a sense of belonging and attachment to community (Statistics Canada, 2021).

Another factor contributing to feelings of social isolation and loneliness is compounded by the enormous geography of Canada. With most urban centres situated along the border with the United States, most rural communities do not have any infrastructure to support digital technologies, which, in turn, essentially cuts these individuals, their families, and other community members off from vital mental health services. According to a 2019, Statistics Canada survey, *Internet Connectivity: Technology, Service Availability and Cost*, "Nearly one in five rural households (19%) without Internet identified service quality as a reason to have no Internet, compared with 2% of urban households" (Statistics Canada, 2019, p. 1). Even worse, for individuals living with illness and/or (dis)ability living in rural communities, access to

medical and mental health professionals exacerbates their stressors. According to Wilson et al., in their 2020 article, *Progress Made on Access to Rural Health Care in Canada*, reveal that those who live in more rural settings typically struggle to appeal to general practitioners and in keeping them in practice (Wilson et al., 2020). With a global shortage of qualified physicians, the situation is made worse in rural Canada as most settings do not have the basic infrastructure to offer telehealth services, where individuals and families require referrals to mental health supports.

Impacts on Family Relationships

Families may experience increased feelings of resentment, guilt, blame, or hopelessness, and while caregivers step up with daily care routines, these parents, experience a kind of psychological distancing or dissociation from their child experiencing illness and/or (dis)ability (Rolland, 2018). Consequently, the child or youth feels resentful, engages in guilt tactics, blame games, and overall feels rejected, inadequate, and that they are a burden within the family (Rolland, 2018). Further, families that expect continued illness and/or (dis)ability in their loved one may experience emotions similar to the impending or actual death of the child as everyone lives with daily uncertainty alongside of a kind of ambivalence between feeling hopeful and hopeless hope (Rolland, 2018). Rolland lays out a table that describes the phases of anticipatory loss in relation to the type of illness. These include: “Possible vs. probable vs. inevitable loss; threat of death, disability, and/or suffering; physical and/or cognitive disability phase of illness or genetic risk phase of family and individual development multigenerational experience with illness and loss [and] belief systems” (Rolland, 2018, p. 161). Significant to these families’ experiences are potential life-long feelings of guilt and shame as they desire their loved one’s death or wish for an end to their suffering (Rolland, 2018). When the individual experiences

increased distress, they may state that they would rather die than to continue with their suffering (Rolland, 2018). The individual living with the illness and/or (dis)ability is often made to feel that they are “bad” for having these thoughts (Rolland, 2018).

As evidenced in a study by Williams-Reade et al., (2020), *Pediatric Chronic Illness Management: A Qualitative Dyadic Analysis of Adolescent Patient and Parent Illness Narratives*, their study reflects the perspectives children and youth diagnosed with a chronic illness, and their immediate families develop maladaptive parental coping strategies. These coping strategies range from worrying and denying, to feeling overwhelmed or minimizing the illness, to controlling and withdrawing emotionally, psychologically, or physically, and, finally, blaming or resenting, potentially with devastating consequences. The authors reveal through child/youth and parent interviews how each demographic reacts or responds to the continuing diagnostics of illness and the similarities in the narratives presented. For example, parents often indicate that they feel responsible for their child’s health care routines as they tried to allay the child’s sense of increasing fear and/or suffering (Williams-Reade et al., 2020). These same children or youth commonly deny or downplay the severity of their symptoms, while refusing to participate in their health care management (Williams-Reade et al., 2020). A common theme emerged around parents who felt overwhelmed by their child/youth’s chronic illness, yet that same child/youth would downplay the seriousness of their condition to calm their parent’s fears (Williams-Reade et al., 2020). Many children and youth expressed feeling as though they were a burden on the entire family, and while their illness and/or (dis)ability needs may increase, they develop coping strategies that include emotional and/or physical distancing as they recognize their parent’s level of anxiety and do not wish to contribute to that anxious state (Williams-Reade et al., 2020). These children and youth recognize early in their lives that their primary

caregiver is unable to cope with the continuum of care required and instantly knows when that parent is feeling overwhelmed and anxious (Williams-Reade et al., 2020). Alternatively, “parents [who] took a more controlling stance in response to illness management. spent a significant amount of time interacting with the medical community, seeking alternative treatments, and in discussion with their children about the illness details” (Williams-Reade et al., 2020, p. 141). The implication for these families is how often the child or youth emotionally withdraw from their primary caregivers even as they experienced feelings of being overwhelmed when their illness was discussed with other clinicians (Williams-Reade et al., 2020). Tragically, “these parents took a more controlling stance and the children attempted management efforts but were easily overwhelmed. Parents in this group reported their desire to exert control over, rather than be controlled by the illness” (Williams-Reade et al., 2020, pp. 141-42). As a result, Williams-Reade et al. noted how the child or youth felt that their mother or father related to their loved one’s illness better than to their relationship with them (Williams-Reade et al., 2020). In this study group, the children or youth living with illness and/or (dis)ability often pushed back against their parents or primary caregivers to decrease their parents’ control over their choices (Williams-Reade et al., 2020). Of all themes, the authors note, the one involving blame and resentment is the most harmful. Williams-Reade et al., report how “parents openly admitted to having feelings of anger or resentment toward their children” (Williams-Reade et al., 2020, p. 142), expressing “derogatory comments about their child being a burden and blamed them for the illness or its impact on the family” (Williams-Reade et al., 2020, p. 142). Examples include a mother describing their daughter as “just volatile towards everybody” [and could be] “very vile toward other people. She has a very ugly face at home” (Williams-Reade et al., 2020, p. 142). One “father said that he and his child’s mother had tried “to be sympathetic” but that sometimes

they were “difficult” because (addressing his daughter although she was not in the room) “you cause us to be that way, bitch” (Williams-Reade et al., 2020, p. 142). Subsequently, children and youth felt more outrage, resenting their parents and any decisions that these caregivers made about their health care (Williams-Reade et al., 2020). Often, the child or youth will resort to swearing or ignoring towards their parents, indicating their feelings of hostility, declaring that they do not belong in the family or that the family is not “normal” like other families (Williams-Reade et al., 2020). Parental reactions included becoming,

“tearful, silent, or angry in the initial discussion of these events” until they became aware of how triggering their parenting styles reflected “events from their own childhoods (e.g., divorce of parents, death or serious illness of a parent, childhood abuse); from their adult experiences (e.g., being divorced/separated themselves, being the victim of intimate partner violence); and from their own child’s illness experience (e.g., the child had almost died at some point)” (Williams-Reade et al., 2020, p. 142).

The significant events related to these parent’s own childhood underscores the forms of intergenerational trauma in which a grief narrative is revisited in another form. As Williams-Reade et al., report, “Some parents had grown up around a sick or dying parent or sibling and they based their parenting decisions on these experiences. One parent’s response was to take a more controlling stance which reflected their experience growing up” (Williams-Reade et al., 2020, p. 142). As well, despite learning about a child’s diagnosis, the family is often challenged with creating meaning to their own lived experience as they try to cope with their child’s current health condition and/or (dis)ability (Williams-Reade et al., 2020). At the heart of these conflicts are overall threats to the child’s well-being, which raises feelings of fear along with the worry of their child encountering increased suffering, which, in turn, increases family discord (Williams-

Reade et al., 2020). Indications from Williams-Reade et al., suggest that individuals experiencing chronic illness and their family members may be enduring significant “emotional responses that include hyper-arousal, avoidance, re-experiencing, dissociation, somatic complaints, as well as changes in mood, cognitions, and behavior; these reactions may persist over time and interfere with recovery and/or return to normal activities” (Williams-Reade et al., 2020, p. 144). While too easy to state that these families may be “suffering”, counsellors may recognize the underlying causes for the forms of traumas they likely encountered as children. Mental health supports could include utilize the FSI model, MEND, or other strength-based family interventions to alleviate or reduce to deterioration within families.

Recommendations for Society

According to Wolbring, in their 2011 article, *People with Disabilities and Social Determinants of Health Discourses, the Social Determinants of Health (SDH)*, involve “income and social status, social support networks, education and literacy, employment and working conditions, social environments, physical environments, personal health practices and coping skills, child development, biology and genetic endowment, health services, gender, and culture” (Wolbring, 2011, p. 317).

The author noted at that time that within the UN Convention on the Rights of Persons with Disabilities all social determinants of health areas could be improved (Wolbring, 2011). Despite the intentions of the UN Convention goals, focussing on people with (dis)abilities, only mentioning them for the first time in 2010, there remains significant gaps in all areas of the SDH (Wolbring, 2011). Of note are the major inequities in basic economic necessities of life, affordable accessible housing, access to all services including medical/psycho/social, and employment opportunities to address the increased demands of the cost of living. Wolbring

reinforces how persons with (dis)abilities are not only underrepresented but remain unrecognized as having health care needs, often over their entire lifespans, leading to poor SDH outcomes (Wolbring, 2011).

Along with the Social Determinants of Health, Austin et al, in their 2016 article, *Disability and Exposure to High Levels of Adverse Childhood Experiences: Effect on Health and Risk Behavior*, detail how adverse childhood experiences (ACE's), reinforce the challenges that individuals with (dis)abilities encounter (Austin et al., 2016), as “persons with disabilities ha[ve] received relatively little attention in the research literature” (Austin et al., 2016, p. 30). ACE's (adverse childhood experiences) generally fall into eight categories: “sexual physical emotional [household substance] abuse, adult mental illness, domestic violence in the household, incarceration of a household member, and parental divorce or separation” (Austin et al., 2016, p. 30). Findings demonstrate how childhood experiences often carry life-long impacts on their physical and psychological health (Austin et al., 2016). As well, noting the more ACE's a person experiences, the greater the “risk of poor outcomes—such as smoking, obesity, depression, and ischemic heart disease in adulthood” (Austin et al., 2016, p. 30). Tragically, in people identifying with a (dis)ability, they “were found to have a higher prevalence of health risk behaviors compared to persons without disabilities” (Austin et al., 2016, p. 31), with “(36.5%) than those without disabilities (19.6%)” (Austin et al., 2016, p. 33). The study noted how those children or youth with “high ACE exposure, the risk of current smoking, no recent exercise, obesity, HIV risk behaviors, and all 5 indicators of perceived poor health was significantly higher for those with disabilities compared to those without disabilities” (Austin et al., 2016, p. 34). As well, there is a connection between disability status and poor health outcomes, regardless of their ACE's scores (Austin et al., 2016).

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The implications continue as a person living with (dis)ability experiences their unique situation(s). In Morris et al., (2019), *The Dynamics of Disability: Progressive, Recurrent or Fluctuating Limitations*, propose that due to society's mainstream ideas that (dis)ability limits the quality and quantity of a person's life, reflect whether the condition or situation is seen as permanent and unchanging (Morris et al., 2019). One of the significant issues facing persons with (dis)abilities involves the shifting nature of their condition(s) as each person's lived experience changes depending on several factors, including "periods of good health in between periods of their limitations (on-again/off-again episodes) and/or experience changes in the severity of their limitations over time (worsening, improving, or fluctuating)" (Morris et al, 2019, p. 5). The researchers noted how, persons with (dis)abilities regularly reported how their core lived experiences are not understood nor well represented within research studies or surveys contributing to an overall societal misunderstanding of the needs of these individuals and their families (Morris et al., 2019). Another point in this study recognizes how each of us regardless of our current health states, present vital patterns unique to each of us, at times living with a constantly changing dynamic or fluid conditions (Morris et al., 2019). The results from the study follow from a 2017 Canadian Survey on Disability (CSD), in which the survey "questionnaire [did] not contain a "checklist" of conditions, illnesses, diseases, or injuries where a respondent can report having or not having each condition on the list" (Morris et al., 2019, p. 7). The limitations indicate how of those respondents involved in answering the survey questions, could only register to a maximum of having two primary "condition(s) leading to their limitations [regardless of the] prevalence of a particular condition, disease, or injury type" (Morris et al., 2019, p. 7). The authors recognized that,

“Anxiety is one of the more common conditions leading to a mental health-related disability and is often deemed to be episodic in nature. However, on the 2017 CSD, nearly two in five of those reporting anxiety as a main underlying condition reported having recurrent limitations (one month or more without limitation) and another one in five experienced fluctuating limitations, while a third reported continuous limitations” (Morris et al., 2019, p. 28).

Yet, from a societal perspective, the respondents would likely downplay their mental health state when confronted with barriers that emphasized only the medical or physical nature of their lived experiences, negating their psychological trauma. Recommendations would include guiding governments and social service agencies who engage in surveys to access the individuals with the lived experiences to be directly involved in assessing, developing, implementing, and evaluating any mental health programs. By actively engaging in (dis)ability justice, better outcomes for individuals living with illness and/or (dis)ability is more likely.

Recommendations for Clinical Practice

While the idea of counsellors implementing engaging, meaningful mental health supports to individuals experiencing chronic illness and/or (dis)abilities and their families, there remains the dilemma of society embracing a (dis)ability justice lens that reflects a societal biopsychosocial benefit. Societies struggle to grasp the core concept of fully adopting the values and principles as aligned with (dis)ability justice. When we realize that every person at some point in their lives will directly or indirectly experience a form of (dis)ability, and in that moment of awareness realizing that our lives will never be the same, we have a choice: we can either embrace the inevitable with dignity and respect, or we descend into the traumas that humans experience. We instinctively know that we must reach out for help, and yet, we do not,

and worse, we do not receive the support we need. Consequently, by denying (dis)ability justice, we are harming not only ourselves, but everyone around us.

Recommendations to counsellors and/or clinicians offering supports and services using a (dis)ability justice approach, then, recognizes how limited the literature intersecting between illness and/or (dis)ability and practice continues. Outside of Rolland, MEND, Wood, and a few other individuals dedicated to the concepts of (dis)ability justice from theory into practice, the emerging goals of educating and training, then provide access to individuals living with illness and/or (dis)ability and their families via the medical community, offers a much-needed resource for entire communities. By promoting a (dis)ability justice framework to clinicians, the biopsychosocial aspects of the human condition are fully represented, and counsellors may engage in improving their clients' lives through better mental health and well-being.

Rolland, 1987, reminds practitioners that they need to be mindful of the cultural differences between themselves, the patient, and the family. They recognized that a failure to include individuals with chronic illness and/or (dis)ability and their family in the treatment process would and does result in a lack of basic trust in the biopsychosocial areas of health and potential meaningful resources, such as counselling that is (dis)ability justice centred. To avoid the pitfall of noncompliance and mistrust of practitioners by individuals living with illness and/or (dis)ability, families must be better supported in their cultural needs, their own goals, wants, and needs (Rolland, 1987). The core approach encouraged in Rolland's 1999 article refers to regular "psychological tune ups" when clinicians provide individuals and their family members opportunities to check in when issues or concerns arise (Rolland, 1999). These sessions offer counsellors opportunities at the larger community and societal levels to analyse the intersectionality between institutions, professionals, and clients and families (Rolland, 1999).

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Central to counsellors is understanding how time passing provides an excellent moment for practitioners to consider how long-term chronic illness experiences impacts each person and their family while being mindful of their present and future mental health needs (Rolland, 1999). By 2018, Rolland, in their eBook, zeroes in on the benefits of counsellors adopting the “Family Systems Illness (FSI) model [which] emphasizes interaction and context; individual behavior is viewed within the context in which it occurs” (Rolland, 2018, p. 29). In contrast, the MEND model, which offers a holistic systems approach benefitting not only the individual experiencing illness and/or (dis)ability and their family members, MEND ensures access to group peer-to-peer counselling services, as well as continued community supports long after the initial health crisis. Rolland endorses practitioners to view the individual with chronic illness and/or (dis)ability and their family members as vital to any treatment options and future mental health supports (Rolland, 2018).

From a biopsychosocial approach, counsellors can focus on what Rolland terms as transactional, in which they recognize the individual living with chronic illness and/or (dis)ability and their immediate family as the core component for practitioners to assess beneficial aspects of the family and environments (Rolland, 2018). Rolland reminds us of how a person living with chronic illness faces uncertain financial, familial, housing, healthcare, and psychosocial supports (Rolland, 2018). The core message is that when counsellors involve and include individuals living with chronic illness and their families, they may “avoid unhelpful mind-body divisions” (Rolland, 2018, p. 60). By using “collaborative health care emphasizes the cocreation of narratives about health conditions that incorporate the belief systems of patients, families, and health care providers” (Rolland, 2018, p. 129). As mentioned earlier, when societies embrace, rather than avoid, deny, or destroy that which they fear, they often miss

opportunities to fully embrace the “health meanings derived from larger cultural, macrosocial, economic, political, or institutional forces that are often beyond a patient’s and family’s control” (Rolland, 2018, p. 129). Mental health care practitioners must be alert to the environmental factors that negatively affect health outcomes (Rolland, 2018). Practitioners who develop narratives that reflect the person first from any presenting condition convey respect of that person, thereby building a trusting therapeutic relationship (Rolland, 2018). By coming from an inclusive, social justice lens, counsellors engage in ethical practice, “to challenge and change the systems we work in, particularly hierarchical power relationships that marginalize and subordinate the family” (Rolland, 2018, p. 350). Further to improving the power dynamics that occur between mental health practitioners and individuals living with chronic illness and their families, there needs to be proactive engagement on the part of counsellors to endorse and advocate for universal mental health care access (Rolland, 2018). As well, Rolland recommends that there be significant improvements to psychosocial education that focusses on recognition of families and their loved one’s lifelong health needs, so that counsellors better represent the psychosocial aspects of the individual and their family (Rolland, 2018). Of note concerns how practitioners must embrace “Policies concerning continuing life support and end-of-life decisions, including physician-assisted dying to support patients’ rights, dignity, and control in the dying process” (Rolland, 2018, p. 368). Rolland reminds us that counsellors have a core responsibility to endorse and reinforce that each person’s voice is heard and acknowledged as this is an awareness of respecting autonomy of the person rather than focussing on the chronic illness (Rolland, 2018).

Another consideration for clinical practice is the relationship between clinician, family, and the individual experiencing illness and/or (dis)ability is how to build trust. As Carole

Robinson opens in their 2016 article, *Trust, Health Care Relationships, and Chronic Illness: A Theoretical Coalescence*, the first place a family could encounter negative messages from health care professionals. When their loved one is subsequently diagnosed with a chronic illness and/or (dis)ability, discriminatory and ableist comments that sound, to the family like judgement and blame, contribute to mental health distress or psychological harm. Robinson, an advanced nurse practitioner and faculty member of the University of British Columbia's, School of Nursing, Faculty of Health and Social Development, states their "long-standing interest in health care relationships, that is, the interpersonal relationships between patients, their family members, and the professionals who provide care" (Robinson, 2016, p. 1). Their primary focus of investigating the experiences between individual's chronic pain, and/or their terminal diagnosis centres on pain, symptom management, and palliative care. Their research supports the notion that when a client and their family receive respectful, meaningful health care, their health outcomes are improved with less crisis-driven visits, less subsequent substance use/abuse, less government interventions, and less fractured relationships (Robinson, 2016). At the heart of Robinson's research is the concept that, for a family to feel safe when their loved one is diagnosed with a chronic illness, they must experience trust between those providing care, regardless of whether these persons be a family doctor to a specialist or other health care provider.

Öksüz & Brubaker, in their 2020 article, *Deconstructing Disability Training in Counseling: A Critical Examination and Call to the Profession*, critique the lack of practitioners trained to work with individuals identifying with a (dis)ability and, worse, how few counsellors who may have a (dis)ability themselves or who are actively discouraged from working with persons with (dis)abilities (Öksüz & Brubaker, 2020). The authors argue is that the current prevalence of the "medical model in counseling causes many problems and injustices for clients

with disabilities and contributes their further marginalization” (Öksüz & Brubaker, 2020, p.

4). As all populations age, and more people acquire or live longer with their health conditions, we must concede that counsellors and mental health practitioners will inevitably encounter an individual living with a chronic illness or (dis)ability (Öksüz & Brubaker, 2020).

Burghardt et al., in their 2021 article, *Coming to Critical Disability Studies: Critical Reflections on Disability in Health and Social Work Professions*, emphasize that practitioners and those who engage in critical (dis)ability studies (CDS) scholarship owe society the responsibility of awareness that (dis)ability is a socio-political phenomenon, an intersectionality between body/mind/society (Burghardt et al., 2021). When mental health practitioners fully embrace a biopsychosocial approach, they reduce the stigma and discrimination towards outdated concepts around (dis)ability that assimilation into “normal society” is the only way to exist (Burghardt et al., 2021).

Public Health Applications

Within the province of British Columbia (BC), various provincial governments have attempted to not only address the increasing mental health crises that arose within the last 10 years, but to create ministries and programs that aim to reduce the harms caused by mental health disparities and substance use. In 2015, the province of BC published a paper on their task force findings, promoting policies focussing on improving overall family mental health. Titled, *Families at the Centre: Reducing the Impact of Mental Health and Substance Use Problems on Families*, the language of the paper aims to reach out towards individuals and family members as an endearing component of Canadian society built upon principles of holism, that are relational, multigenerational, family-centred, and communally based (Province of BC, 2015). When a family member does not receive the appropriate mental health supports that assist them, their

family members may also be negatively impacted, which furthers the harms and traumas associated with increased substance-use and continued mental health decline (Province of BC, 2015). The aim, therefore, of the province's programs attempts to address the necessity for improved person and family-centred mental health care, like what the MEND program provides (Province of BC, 2015). One of the core findings from the task force is a reminder that individuals and families already possess core strengths and with the correct resources, they may recover and maintain both mental and physical health (Province of BC, 2015). One potential solution, that the province of BC has adopted in an in-person and online resource hub dedicated to supporting youth and their families. Foundry's goals include offering service providers such as counsellors, psychologists, social workers, and physicians whose focus is to deliver an integrated health care approach that reflects the needs of those ages 12 to 24 (Foundry, 2020). A key area of practice is person-centred, family-based, and aims towards multisystem access and intersectionality, or what Foundry terms, "All services under one roof" (Foundry, 2020, p. 15). Foundry strives towards social justice frameworks that de-institutionalize services while juggling governmental funding models, recognizing a trauma-informed approach, emphasizing safe spaces for young people (Foundry, 2020). In the 2021 appendices to Foundry's initial guide, it is noted that the Canadian social services system is predominantly crisis-management-based and for youth about to or actively experiencing mental health crises, it is a case of a little-to-little-too-late and, consequently, youth may have or will have engaged in harmful behaviours (Foundry, 2021a). Even worse, the lack of direct services means lengthy waitlists and wait times, resulting in tragic outcomes (Foundry, 2021a). Based on the collaborative, integrated approaches utilized by Foundry, there are similar aspects noted in MEND. As Mathias et al, 2021, review in their article, *Foundry: Early learnings from the implementation of an integrated youth service*

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network, this provincially funded resource aims to spread beyond urban centres into rural communities who require culturally sensitive service providers who possess the capacity to offer “collaborative, interdisciplinary and innovative patient- and family-oriented care environment” (Mathias et al., 2021, p. 2). However, Foundry has yet to adopt a broader aspect of counselling supports that integrate (dis)ability justice frameworks within their delivery model. There remains a need to recognize and respect the lived experiences of all citizens and the Foundry or any other federal or provincially funded frameworks can work to include the lived experiences of those with chronic illness and any accompanying mental health supports they require (Mathias et al., 2021).

Another set of implications in which applications zeroing in on (dis)ability justice and improved counselling will present themselves in the form of yet another Statistics Canada survey requesting individuals to report more detailed information regarding their health care status (Statistics Canada, 2022). The current survey requires participants to declare the some of the following health-related conditions, including those related to a person’s diagnosis of (dis)ability, the age at which it occurred, how the condition impacts their day-to-day lives, and other aspects associated with the determinants of health. For the first time, the survey also acknowledges key areas related to poverty, overall health along with mental health status, and perceived bias related to (dis)ability (Statistics Canada, 2022). The implications for mental health services once the survey concludes and data is compiled and analyzed will indicate future directions that could offer policies and funding directly to those who require mental health supports.

Final Reflection: Living Legacy of (Dis)ability Justice

One indirect, yet profound person of influence, Luke Melchior, another person living with Duchenne Muscular Dystrophy (DMD), provided what really mattered to those living with illness and/or (dis)ability. Like Terry Fox, Luke had a kind of energy that could be described as a (dis)ability activist, calling out our death-denying culture while reinforcing his profound desire to live as fully as possible. Luke fought for what is important, the right to exist, to promote our core strengths, and to leave a legacy that any who knew him would endorse. Due to Luke's approach towards any issues that affected his life in a negative way, his legacy is about developing and putting voice to what matters and not giving up, no matter the circumstances. For example, the National Film Board of Canada chose him to profile a particular lived experience and filmed a documentary in 2003, entitled, *Bearing Witness: Luke Melchior*, directed by Dan Curtis, who focussed on Luke's personal narrative and choices, giving Luke voice to what mattered to him, demonstrating his persistence to live life on his own terms.

With Luke's death at age 48, inspires others to leave a legacy that carries meaning to others, to offer them the opportunity to approach their own lived experiences as growth, and to engage in what creates meaning to and for them. One of the most significant moments in Luke's obituary published in the Victoria Times Colonist, mentions his persistence to, "challenge beliefs right from the beginning the first man with DMD on Vancouver Island to fight to gain access to non-invasive ventilation" (Times Colonist, 2021, para. 1), and to live with live-in caregivers for the next several decades (Times Colonist, 2021). Based on the urgency of those who have chronic illness and/or (dis)abilities, and their awareness of living on "borrowed time", there are compelling arguments to pursue goals towards (dis)ability justice that will benefit all.

Conclusion

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This Capstone project centres on the idea that all persons, regardless of their health status have fundamental rights to live a full and meaningful existence through fulfilling their biopsychosocial needs, and, consequently, that (dis)ability justice is a construct that requires a thoughtful and action-based approach designed to reduce or eliminate discrimination and harm. Based on the focus and research critically examining mental health supports to individuals living with serious health conditions and their families, the Canadian historical context regarding stereotypes, deficit-based narratives regarding (dis)ability, death-denying, and vulnerability. The lack of services representing the biological, psychological, and sociological aspects of the human condition persist in reinforcing negative narratives, ones that must be resisted. By providing a (dis)ability justice lens on the needs for person-centred, strength-based approaches, we argue that the societal need for these programs such as what MEND offers, ensures numerous individual, community, and societal benefits. These benefits include overall individual health and family mental health, better integration into all areas of community and society regardless of language, culture, or other markers of status. The cost-benefit analysis demonstrated by the MEND program reinforces the need for integrated health care for persons impacted by health conditions and their family. Other approaches, models, and programs are presented, noting their core strengths and, in some cases, suggesting where improvements could be realized. As well, this Capstone project emphasizes how, with the right types of supports, no BodyMind ever need to be left behind; instead, the individual living with health conditions may contribute in as meaningful a way as any other person.

References

- American Psychiatric Association. (2013). Somatic Symptom and Related Disorders. In *Diagnostic and statistical manual of mental disorders* (5th ed.).
<https://doi.org/10.1176/appi.books.9780890425596.dsm09>
- American Psychiatric Association. (2013). Trauma-and Stressor-Related Disorders. In *Diagnostic and statistical manual of mental disorders* (5th ed.).
<https://doi.org/10.1176/appi.books.9780890425596.dsm07>
- American Psychological Association. (2013). *Integrated Health Care*.
<https://www.apa.org/health/integrated-health-care>
- Andrews, E. E., Ayers, K. B., Brown, K. S., Dunn, D. S., & Pilarski, C. R. (2021). No Body is Expendable: Medical Rationing and Disability Justice During the COVID-19 Pandemic. *American Psychologist*, 76(3), 451–461. <http://dx.doi.org/10.1037/amp0000709>
- Angus Reid Institute. (2021). *Canadians Concerned About Disability Poverty, On-Board with Proposed New National Benefit: Survey of Canadians Living with Disability Underlines Relative Poverty, Other Social Barriers*. https://angusreid.org/wp-content/uploads/2021/06/2021.06.22_Disability_Poverty_Benefit.pdf
- Austin, A., Herrick, H., Proescholdbell, S., & Simmons, J. (2016). Disability and Exposure to High Levels of Adverse Childhood Experiences: Effect on Health and Risk Behavior. *North Carolina Medical Journal*, 77(1), 30-36. <https://doi.org/10.18043/ncm.77.1.30>
- Berne, P., Morales, A.L., Langstaff, D., & Invalid, S. (2018). Ten Principles of Disability Justice. *WSQ: Women's Studies Quarterly*, 46(1), 227-230.
<https://doi.org/10.1353/wsqa.2018.0003>

- Burghardt, M., Edelist, T., Schormans, A. F., & Yoshida, K. (2021). Coming to Critical Disability Studies: Critical Reflections on Disability in Health and Social Work Professions. *Canadian Journal of Disability Studies*, 10(1), 22–53.
<https://doi.org/10.15353/cjds.v10i1.743>
- Canter, K. S., Christofferson, J., Scialla, M. A., & Kazak, A. E. (2019). Technology-Focused Family Interventions in Pediatric Chronic Illness: A Systematic Review. *Journal of Clinical Psychology in Medical Settings*, 26(1), 68–87. <https://doi.org/10.1007/s10880-018-9565-8>
- Coelho, A., & Barbosa, A. (2017). Family Anticipatory Grief: An Integrative Literature Review. *American Journal of Hospice & Palliative Medicine*, 34(8), 774–785.
<https://doi.org/10.1177/1049909116647960>
- Cotter, A. (2018). *Juristat: Violent Victimization of Women with Disabilities*, 2014. Statistics Canada. 1-34. <https://www150.statcan.gc.ca/n1/en/pub/85-002-x/2018001/article/54910-eng.pdf?st=EwA4s2Es>
- Crow, L. (1996). Including All of Our Lives: Renewing the Social Model of Disability. *ResearchGate*, 1-21.
https://www.researchgate.net/publication/246453360_Including_All_of_Our_Lives_Renewing_the_Social_Model_of_Disability
- Curtis, D. (Director), Symanssky, A., & Lapointe, P. (Producers). (2003). *Bearing Witness: Luke Melchior* [Film]. National Film Board of Canada.
https://www.nfb.ca/film/bearing_witness_luke_melchior/?fbclid=IwAR0-UozAjs22bev_lsOHqsD9JvtwQENW4S27YIfApqgtPwVsjPx18RLEcho

Dictionary.com. (n.d.). *Ableism*. Retrieved September 27, 2022, from

<https://www.dictionary.com/browse/ableism>

Dictionary.com. (n.d.). *Social Justice*. Retrieved March 10, 2021, from

<https://www.dictionary.com/browse/social-justice>

Distelberg, B., Williams-Reade, J., Tapanes, D., Montgomery, S., & Pandit, M. (2014).

Evaluation of a Family Systems Intervention for Managing Pediatric Chronic Illness:

Mastering Each New Direction (MEND). *Family Process*, 53(2), 194–213.

<https://doi.org/10.1111/famp.12066>

Distelberg, B., Castronova, M., Tapanes, D., Allen, J., & Puder, D. (2020). Evaluation of the

Healthcare Cost Offsets of Mend: A Family Systems Mental Health Integration

Approach. *Family Process*, 60(2), 1-15. <https://doi.org/10.1111/famp.12564>

Downie, J., & Schuklenk, U. (2021). Social determinants of health and slippery slopes in assisted

dying debates: lessons from Canada. *Journal of medical ethics*, 47(10), 662–

669. <https://doi.org/10.1136/medethics-2021-107493>

Driedger, D. (2018). Organizing for Change: The Origins and History of the Manitoba League of

the Physically Handicapped, 1967–1982. In N. Hansen, R. Hanes, & D. Driedger (Eds.),

Untold Stories: A Canadian Disability History Reader (pp. 221-242). Canadian Scholars.

<https://bookshelf.vitalsource.com/books/9781773380476>

Emerson, N. D., Morrell, H. E. R., Neece, C., Tapanes, D., & Distelberg, B. (2019). Longitudinal

Model Predicting Self-Concept in Pediatric Chronic Illness. *Family Process*, 58(1), 100-

113. <https://doi.org/10.1111/famp.12361>

Foundry. (2021). *Forging the Path Forward*. [https://foundrybc.ca/wp-](https://foundrybc.ca/wp-content/uploads/2021/07/SERV_ServiceModelGuideV.1.1_20210521.pdf)

[content/uploads/2021/07/SERV_ServiceModelGuideV.1.1_20210521.pdf](https://foundrybc.ca/wp-content/uploads/2021/07/SERV_ServiceModelGuideV.1.1_20210521.pdf)

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Foundry. (2021). *Appendices*. [https://foundrybc.ca/wp-](https://foundrybc.ca/wp-content/uploads/2021/07/SERV_ServiceModelGuideAppendixV.1_20210308.pdf)

[content/uploads/2021/07/SERV_ServiceModelGuideAppendixV.1_20210308.pdf](https://foundrybc.ca/wp-content/uploads/2021/07/SERV_ServiceModelGuideAppendixV.1_20210308.pdf)

Foundry, (2020), *Service Model Guide 1. Overview of Service Model*.

Forbat, L. (2020). The Role and Value of Family Therapy for People Living With Cancer: A Rapid Review of Recent Evidence. *Current Opinion in Supportive & Palliative Care*, 14(3), 263–269. <https://doi.org/10.1097/SPC.0000000000000504>

Galer, D. (2018). Building an Accessible House of Labour: Work, Disability Rights, and the Canadian Labour Movement. In N. Hansen, R. Hanes, & D. Driedger (Eds.), *Untold Stories: A Canadian Disability History Reader* (pp. 268-281). Canadian Scholars. <https://bookshelf.vitalsource.com/books/9781773380476>

Guidry-Grimes, L., Savin, K., Stramondo, J. A., Reynolds, J. M., Tsaplina, M., Burke, T. B., Ballantyne, A., Kittay, E. F., Stahl, D., Scully, J. L., Garland-Thomson, R., Tarzian, A., Dorfman, D., & Fins, J. J. (2020). Disability Rights as a Necessary Framework for Crisis Standards of Care and the Future of Health Care. *The Hastings Center report*, 50(3), 28–32. <https://doi.org/10.1002/hast.1128>

Hanes, R. (2018). Service Clubs and the Emergence of Societies for Crippled Children in Canada: The Rise of the Ontario Society for Crippled Children, 1920–1940. In N. Hansen, R. Hanes, & D. Driedger (Eds.), *Untold Stories: A Canadian Disability History Reader* (pp. 140-160). Canadian Scholars. <https://bookshelf.vitalsource.com/books/9781773380476>

Harris, D.L., & Winokuer, H. R. (2019). *Principles and Practice of Grief Counseling* (3rd ed.). [eBook]. Springer Publishing Company. <https://bookshelf.vitalsource.com/books/9780826173331>

Health Canada. (2022). *Final Report of the Expert Panel on MAiD and Mental*

Illness. <https://www.canada.ca/content/dam/hc-sc/documents/corporate/about-health-canada/public-engagement/external-advisory-bodies/expert-panel-maid-mental-illness/final-report-expert-panel-maid-mental-illness/final-report-expert-panel-maid-mental-illness.pdf>

Ingham, E. (2018). Attitudes Towards Disability in Society Viewed Through the Lens of Critical Disability Theory: An Analysis of Me Before You. *Counselling Psychology Review*, 33(1), 2–12.

https://www.researchgate.net/publication/327498942_Attitudes_towards_disability_in_society_viewed_through_the_lens_of_critical_disability_theory_An_analysis_of_'Me_Before_You'

Ingham, E. (2018). The (Physically) Wounded Healer: The Impact of a Physical Disability on Training and Development as a Counselling Psychologist: A Case Study. *European Journal of Counselling Psychology*, 7(1), 31–46.

<https://ejcop.scholasticahq.com/article/17011-the-physically-wounded-healer-the-impact-of-a-physical-disability-on-training-and-development-as-a-counselling-psychologist-a-case-study>

Loma Linda University Health. *MEND Outpatient Program*. Retrieved February 2, 2022, from <https://lluh.org/behavioral-health/our-services/mend-outpatient-program>

Malacrida, C. (2018). Work, Education, and Privilege: An Alberta City’s Parasitical Relationship to Its Total Institution for “Mental Defectives”. In N. Hansen, R. Hanes, & D. Driedger (Eds.), *Untold Stories: A Canadian Disability History Reader* (pp. 163-178). Canadian Scholars. <https://bookshelf.vitalsource.com/books/9781773380476>

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- Mathias, S., Tee, K., Helfrich, W., Gerty, K., Chan, G., & Barbic, S. P. (2021). Foundry: Early Learnings From the Implementation of an Integrated Youth Service Network. *Early Intervention in Psychiatry, 16*(4), 410-418. <https://doi.org/10.1111/eip.13181>
- McGillivray, K. (2018). Living in the Midst: Re-imagining Disability Through Autobiography. In N. Hansen, R. Hanes, & D. Driedger (Eds.), *Untold Stories: A Canadian Disability History Reader* (pp. 356-367). Canadian Scholars.
<https://bookshelf.vitalsource.com/books/9781773380476>
- Minich, J. A. (2016). Enabling Whom? Critical Disability Studies Now. *Lateral, 5*(1), 1-7.
<https://doi.org/10.25158/L5.1.9>
- Morris, S., Fawcett, G., Timoney, L., Hughes, J. (2019). *The Dynamics of Disability: Progressive, Recurrent or Fluctuating Limitations*. Statistics Canada. 1-31.
<https://www150.statcan.gc.ca/n1/en/pub/89-654-x/89-654-x2019002-eng.pdf?st=iK8Bbjlq>
- Morris, S., Fawcett, G., Brisebois, L., & Hughes, J. (2018). *Canadian Survey on Disability: A Demographic, Employment and Income Profile of Canadians with Disabilities Aged 15 Years and Over, 2017*. Statistics Canada. 1-25.
<https://www150.statcan.gc.ca/n1/en/pub/89-654-x/89-654-x2018002-eng.pdf?st=Csu7IASjl>
- Naito, R., Leong, D. P., Bangdiwala, S. I., McKee, M., Subramanian, S. V., Rangarajan, S., Islam, S., Avezum, A., Yeates, K. E., Lear, S. A., Gupta, R., Yusufali, A., Dans, A. L., Szuba, A., Alhabib, K. F., Kaur, M., Rahman, O., Seron, P., Diaz, R., Puoane, T., ... Yusuf, S. (2021). Impact of Social Isolation on Mortality and Morbidity in 20 High-

- Income, Middle-income and Low-income Countries in Five Continents. *BMJ global health*, 6(3), 1-7. <https://doi.org/10.1136/bmjgh-2020-004124>
- Öksüz, E. E., & Brubaker D. M. (2020). Deconstructing Disability Training in Counseling: A Critical Examination and Call to the Profession, *Journal of Counselor Leadership and Advocacy*, 7 (2), 163-175. <https://doi.org/10.1080/2326716X.2020.1820407>
- Overton, B. L., & Cottone, R. R. (2016). Anticipatory Grief: A Family Systems Approach. *The Family Journal*, 24(4), 430–432. <https://doi.org/10.1177/1066480716663490>
- Oxford Reference (n.d.). *Overview Social Justice*. Retrieved March 10, 2021, from <https://www.oxfordreference.com/view/10.1093/oi/authority.20110803100515279>
- Preston, J. (2017). *The Fantasy of Disability: Images of Loss in Popular Culture*. [eBook]. Taylor & Francis. <https://bookshelf.vitalsource.com/books/9781317032014>
- Province of British Columbia: Family Mental Health & Substance Use Task Force. (2015). *Families at the centre: Reducing the Impact of Mental Health and Substance Use Problems on Families*. https://www2.gov.bc.ca/assets/gov/health/managing-your-health/mental-health-substance-use/child-teen-mental-health/families_at_the_centre_full_version.pdf
- Rivas, C., Tomomatsu, I. and Gough, D. (2021). The Many Faces of Disability in Evidence for Policy and Practice: Embracing Complexity. *Evidence & Policy*, 17(2), 191-208. <https://doi.org/10.1332/174426421X16147909420727>
- Robinson, C. A. (2016). Trust, Health Care Relationships, and Chronic Illness: A Theoretical Coalescence. *Global Qualitative Nursing Research*, 3, 1-11. <https://doi.org/10.1177/2333393616664823>

- Rogalla, K. B. (2020). Anticipatory Grief, Proactive Coping, Social Support, and Growth: Exploring Positive Experiences of Preparing for Loss. *Omega: Journal of Death & Dying*, 81(1), 107–129. <https://doi.org/10.1177/0030222818761461>
- Rolland, J. S. (1987). Family Illness Paradigms: Evolution and Significance. *Family Systems Medicine*, 5(4), 482-503. <https://doi.org/10.1037/h0089735>
- Rolland, J. S. (1999). Parental Illness and Disability: A Family Systems Framework. *Journal of Family Therapy*, 21(3), 242–266. <https://doi.org/10.1111/1467-6427.00118>
- Rolland, J. S. (2018). *Helping Couples and Families Navigate Illness and Disability*. [eBook]. Guilford Press. <https://bookshelf.vitalsource.com/#/books/9781462534968/>
- Schalk, S. (2017). Critical Disability Studies as Methodology. *Lateral*, 6(1), 1-4. <https://doi.org/10.25158/L6.1.13>
- Soetemans, J. K., & Jackson, L. M. (2021). The Influence of Accessibility on Perceptions of People with Disabilities. *Canadian Journal of Disability Studies*, 10(1), 185-206. <https://doi.org/10.15353/cjds.v10i1.734>
- Statistics Canada. (2022). *Canadian Survey on Disability (CSD)*. Retrieved on July 21, 2022 from, <https://www.statcan.gc.ca/en/survey/household/3251>
- Statistics Canada. (2021). *Canadian Social Survey: Loneliness in Canada*. <https://www150.statcan.gc.ca/n1/daily-quotidien/211124/dq211124e-eng.pdf>
- Statistics Canada. (2019). *Internet Connectivity: Technology, Service Availability and Cost*. https://www150.statcan.gc.ca/n1/en/daily-quotidien/190225/dq190225c-eng.pdf?st=_gd8q_d4
- Tapanes, D., Distelberg, B. J., Williams-Reade J., & Montgomery, S. (2015). Mastering Each New Direction (MEND): A Biopsychosocial Intervention for Pediatric Chronic Illness.

Journal of Family Psychotherapy, 26(1), 3-8.

<https://doi.org/10.1080/08975353.2015.1002735>

The Abolition and Disability Justice Coalition. (n.d.). *Glossary*. Retrieved March 10, 2021, from

<https://abolitionanddisabilityjustice.com/glossary/>

Times Colonist. (2021, December 2) *Luke A. Melchior*. Legacy.

<https://www.legacy.com/ca/obituaries/timescolonist/name/luke-melchior->

[obituary?pid=200738960&utm_source=facebook&utm_medium=social&utm_campaign](https://www.legacy.com/ca/obituaries/timescolonist/name/luke-melchior-)

[=obitsharebeta&fbclid=IwAR3xiFNi3sLPpBoPAua80whF3WE6ceciXEHJjS0qSti2YMi](https://www.legacy.com/ca/obituaries/timescolonist/name/luke-melchior-)

[4hgXXTgphyY](https://www.legacy.com/ca/obituaries/timescolonist/name/luke-melchior-)

Turcotte, P. B. (2018). Disability as Social Threat: Examining the Social Justice Implications of

Canada's Eugenic History. In N. Hansen, R. Hanes, & D. Driedger (Eds.), *Untold*

Stories: A Canadian Disability History Reader (pp. 179-195). Canadian Scholars.

<https://bookshelf.vitalsource.com/books/9781773380476>

University of Rochester Medical Center. *The Biopsychosocial Approach*. Retrieved March 23,

2022, from

<https://www.urmc.rochester.edu/MediaLibraries/URMCMedia/education/md/documents/>

[biopsychosocial-model-approach.pdf](https://www.urmc.rochester.edu/MediaLibraries/URMCMedia/education/md/documents/)

Wendell, S. (1996). *The Rejected Body*. Taylor & Francis.

<https://bookshelf.vitalsource.com/books/9781135770402>

Wendell, S. (2013). Unhealthy Disabled: Treating Chronic Illnesses as Disabilities. In L. J. Davis

(Ed.), *The Disability Studies Reader* (4th ed., pp.161-173). Routledge. <http://ieas->

[szeged.hu/downtherabbithole/wp-content/uploads/2018/02/Lennard-J.-Davis-ed.-The-](http://ieas-szeged.hu/downtherabbithole/wp-content/uploads/2018/02/Lennard-J.-Davis-ed.-The-)

[Disability-Studies-Reader-Routledge-2014.pdf#page=170](http://ieas-szeged.hu/downtherabbithole/wp-content/uploads/2018/02/Lennard-J.-Davis-ed.-The-)

- Williams-Reade, J. M., Tapanes, D., Distelberg, B. J., & Montgomery, S. (2020). Pediatric Chronic Illness Management: A Qualitative Dyadic Analysis of Adolescent Patient and Parent Illness Narratives. *Journal of Marital and Family Therapy*, 46(1), 135–148. <https://doi.org/10.1111/jmft.12377>
- Wilson, C. R., Rourke, J., Oandasan, I. F., & Bosco, C. (2020). Progress Made on Access to Rural Health Care in Canada. *Canadian Family Physician*, 66(1), 31-36. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7012120/>
- Wolbring, G. (2011). People With Disabilities and Social Determinants of Health Discourses. *Canadian Journal of Public Health*, 102(4), 317-319. <https://doi.org/10.1007/BF03404058>
- Wolbring, G., & Ball, N. (2018). History of Science and Technology and Canadians with Disabilities. In N. Hansen, R. Hanes, & D. Driedger (Eds.), *Untold Stories: A Canadian Disability History Reader* (pp. 306-319). Canadian Scholars. <https://bookshelf.vitalsource.com/books/9781773380476>
- Wood, B. L. (1993). Beyond the “Psychosomatic Family”: A Biobehavioral Family Model of Pediatric Illness. *Family process*, 32(3), 261-278. <https://doi.org/10.1111/j.1545-5300.1993.00261.x>
- Wood, B. L., Klebba, K. B., & Miller, B. D. (2000). Evolving the Biobehavioral Family Model: The Fit of Attachment. *Family Process*, 39(3), 319–344. <https://doi.org/10.1111/j.1545-5300.2000.39305.x>
- Wood, B. L., Miller, B. D., & Lehman, H. K. (2015). Review of Family Relational Stress and Pediatric Asthma: The Value of Biopsychosocial Systemic Models. *Family Process*, 54(2), 376-389. <https://doi.org/10.1111/famp.12139>