

The time(s) of our lives: Exploring and opening up alternative temporalities
through the experience of disability

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Child and Youth Studies

Submitted in partial fulfillment
of the requirements for the degree of

Master of Arts

Faculty of Social Sciences, Brock University
St. Catharines, Ontario

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Abstract

The purpose of this qualitative study was to understand how some relate to time atypically and how, precisely through that relation, they help to disclose possibilities for alternative ways of being more generally. Both the COVID-19 pandemic as well as increasing threats of climate change have engendered an appreciation of the precariousness of our existence; in short, these crises have illuminated the inevitability of an uncertain future both immediately and in the long term. Despite the loom, the ways in which we live our lives in the dominant culture of Western society reflects a linear, future oriented temporality where able-bodied citizens often strive for progress and advancement, transformation, and ultimately mastery of the environment. Other temporalities exist, however, such as those shared by people whose bodily experiences construct their social realities in unconventional ways. Often it is their diagnosis that puts them out of line both with developmental time and fundamentally the neoliberal ethos of a productive life. This study strove to disrupt the domination of linear time and opposingly argued that these alternative relationships with time may be more well suited to the precarious nature of our lives. Guided by Rosemarie Garland-Thomson's (2012) bioethical assertion that we might want to conserve rather than eliminate disability, I sought to uncover alternative temporalities in the hopes of disclosing their generative potential. Four memoirs written by parents of children with diverse disabilities were used as qualitative data to convey the experience of disability, temporalities and alternative ways of being in the world. The findings highlight opportunities for rethinking the ways in which we perceive and interact with time.

Acknowledgements

I would like to articulate sincere appreciation to my supervisor Dr. Donato Tarulli for his mentorship and guidance.

I would also like to express gratitude to Dr. Hannah Dyer and Dr. Heather Ramey, my committee members, as well as Dr. Yani Hamdani, my external examiner, for the generous time they have provided me.

Thank you to my parents for supporting my progress and success. I am so grateful for our time together.

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Chapter 1: Introduction

1. Background

Precarity is not typically conceptualized as an existential problem. It is often studied in relation to economics—for example, the precariousness of employment or of the labour market (Lewchuk & Laflèche, 2016). However, in connoting uncertainty and instability, precarity has a broader relevance to life more generally. The COVID-19 pandemic has unquestionably communicated to beings across the globe that life is insecure and unpredictable. The climate crisis has engendered a similar appreciation of the precariousness of our existence. The well documented global average temperature increase, the rise in sea levels and altering weather patterns have exposed future environmental, socio-economic and security impacts to domestic governments (Oxford Research Group, 2008). In short, we can no longer be certain of what the future will hold. While this uncertainty should surely occasion new efforts to safeguard our future, it might also be leveraged to reinvigorate a concern about our well-being in the present.

This study seeks to pursue questions about time consciousness, hegemonic temporality, the precariousness of our existence, and the temporal experiences of people with disabilities. The emphasis will be on how current threats to our world and environment offer the opportunity to reflect on the precarity of our lives and the ways in which we relate to and interact with time. More specifically, it intends to disrupt the ideal trajectory of human advancement, progress and mastery, which is inherently linear and future oriented, not to mention reflective of hegemonic temporality. Despite our universal condition of precariousness, the temporality of the reigning dominant culture of the industrialized West (e.g., Britain, France, United States, Canada)¹ argues that stability can be achieved, and the future controlled. This pervasive ideological value system is carried out through a mass persuasion of civilization to develop as per standardized temporal norms and milestones reflective of the priorities of modernity. This thesis intends to follow other scholars in the critical disability studies field as well as feminist-queer scholars who have articulated this relationship in the past. Researchers such as Alison Kafer (2013), Shelley Tremain (2021), Jennifer Scuro (2017) and Eva Feder Kittay (2020) have long argued that

¹ The geographic “West” will be utilized throughout this work referencing industrialized societies (e.g., Western Europe, North America) characterized by neoliberal modes of rule (e.g., technology, mass production, democratic political systems, urbanization) (Browne, 2001).

disability and illness, amongst the many other diverse dimensions of identity², liberate individuals from corresponding with the dictates and constraints of linear, progressive time. Each argues that the presence of disability and illness presents challenges to the modern subject's understanding of employing the present moment as a conduit to future function. Both disability and illness trouble the valuing of the present moment only as a starting point towards something other than the present (i.e., the future).

In the next several decades of environmental, economic, political, cultural and technological upheaval, the precariousness of our existence is sure to be revealed and will likely be too large to ignore. That said, I seek to disclose alternative temporalities that provide a wider range of options for thinking about time; it is about bringing alternative temporalities—some of which orient us differently to the present—into view. Alternative temporalities, defined in this work as flexible and alternative approaches to normative time frames, such as those inhabited by disabled people and those close to them, may accord with such an alteration. Perhaps there is something to be learned from people whose bodies do not match up to the “standard”, both physically, psychologically and ultimately, temporally. What happens when one is unable to live linearly?

2. Research Purpose and Aims

The purpose of this research study is to understand how some relate to time atypically. In the revelation of temporal difference, I aim to showcase the generativity of alternative ways of being in the world. I will argue that these alternative temporalities may offer cultural contributions in that they may be more well suited to the precarious nature of our lives, contrary to the hegemonic relationship with time the dominant culture currently undertakes.

I will begin by exploring some of the assumptions underlying linear temporality that influence Western neoliberal society. It is my intent, more specifically, to showcase how future-oriented temporality is reflected in our institutions of child development, such as in developmental discourse, education and play. Due to this emphasis on future orientation, this work argues that temporal linearity has manifested into an unquestioned facet of child-rearing, which is taken for granted, and, of course, value laden. The value is precisely in the orientation

² When referencing dimensions of identity, I refer to Traustadóttir's (2006) conceptualizations of social categories, including race, class, age, sexuality, coming together to interlock categories of experience as they simultaneously structure people's lives.

to the future, where linear time seeks to develop particular beings—beings who are autonomous, competitive and productive. Such ideals are rooted in history and in the Enlightenment (Fisher & Goodley, 2007; Baynton, 2011; Hutchinson, 2005). I will then discuss the pervasiveness of normality, reflective of such ideals, and its inherent tendency to marginalize. In saying this, I conclude the first major section of the paper with the argument that those who do not fit into the linear narrative are “temporally segregated” and, robbed of an imagined future that is anything but, in Kafer’s (2013) words, “banal and pathetic” (p.2).

In view of this, guided by Rosemarie Garland-Thomson’s (2012) bioethical assertion that we might want to conserve rather than eliminate disability, I propose that it is these individuals—those whose bodies orient them to time differently—who may offer valuable insight into the merits of alternative temporalities and their associated implications for being in the world. In this sense, this work moves from conceptualizing disability through a deficit lens, to conceptualizing disability in terms of its generative potential, in this case as an ethical, epistemological and existential resource for thinking about the nature of time in our lives, ultimately enabling us to revisit our dominant ideas about time and opening up other possibilities for being.

To investigate such a hypothesis, four memoirs will be employed as qualitative data regarding the experience of relating to time atypically. These memoirs are written by a mother and three fathers of children with complex physical and intellectual disabilities—disabilities that have resulted in a development with no predictable trajectory. More than embarking on an investigation of how the children, those explicitly defined as disabled themselves, must grapple with the exclusion from the dominant linear temporal framework, this work intends to leverage the parents’ perspectives regarding their altered relationship with temporality, following their experiences raising their children developing “off-time”. Do the parents display acceptance of alternative timeframes? Are there benefits to living more in the moment, as opposed to instrumentalizing the present? In studying their perspectives, shared through the narratives expressed within their self-constructed memoirs, this research seeks to reveal the possible value for the wider world of their experience.

The theoretical and ethical premise of this work is to suggest—again, following Garland-Thomson (2012)—that perhaps we might seek to conserve disability rather than eliminate it. In order to do this, my general research aims are as follows:

- To understand how people relate to time both from a hegemonic perspective reflective of Western, neoliberal cultures as well as from less typical relationships with time.
- To disrupt the domination of linear time and point out the flaws in such a manifestation by exposing the existence of alternative relationships to time found in the relationship between four parents and their children.
- To explore the idea that alternative relationships with time are rich with value, insight and potential.

My overarching research question is: Are there insights to be gained from people who interact with time differently?

Thinking with this question, and those that emerge through my research, will provide new discernments and expand upon existing insights into the case for conserving disability (see Garland-Thomson, 2012). These insights can open possibilities for rethinking how we interact with time and ultimately, I suppose, how we interact with each other. My rationale for pursuing this research is to open up possibilities for alternative ways of being, more generally. As this research will reveal, those who have been unable to match the imagined ideal developmental trajectory, as defined by the dominant, future-oriented temporality of the society at large, have been marginalized and excluded from positions of value. These findings will perhaps counter such a perspective by exposing the generative potential and value of the lessons of disability.

3. Key Terminology

The following section is intended to contextualize key terminology for the reader. The inclusion of each term is to offer an initial orientation to the associated concept, with the understanding that more nuanced aspects of these terms will emerge as they are encountered in the context of this paper.

Time. For the purpose of my research, “time” will be utilized to represent the entity that allows for change (Fiocco, 2017). Time is an ever-present feature of our world with both ontological and epistemological properties. It cannot be separated from the spatial context; it is an inextricable facet of the ways in which humanity exists and operates within the world (Compton-Lilly, 2013).

Temporality. The term “temporality” refers to the state of existing within or having some relationship with time. In the social sciences, it is typically studied with respect to the human perception of time and the social organization of time (Ialenti, 2020). I will use this term when referring to the epistemological constructions of how an individual (or society at large) interacts with time in their daily lives. Of course, the ontological construction of time posits that we exist within time, in the sense that change—underlying temporal moments—is at the core of our existence (Fiocco, 2017). Nonetheless, we can also affect and construct time, which the example of linear temporality and its focus on the future and “endpoint” is perfectly representative of (Uprichard, 2008). Nuances around temporality will be disclosed as I consider the work of notable scholars, including Alison Kafer (2013), Gary Saul Morson (2013), and Kathryn Bond Stockton (2009), among many others.

Linear life. “Linear life,” as representative of dominant linear temporality, is reflective of both the Enlightenment and modernism (Fisher & Goodley, 2007). The term will be used to represent the dominant view of society, where history is regarded in terms of cumulative, linear progression. In such a sense, the present is a tool to better the future. Siegel (1988) puts it best in saying “Actions in the present [are] assessed in terms of the efficiency of means in achieving ends” (p. 130). This has manifested in our social institutions, such as schools, with their emphasis on “tooling up” for the future.

Productive. The term “productive” will be employed to reflect the ideal characteristic of a Western adult based on neoliberal social/ psychological axioms. In this sense, productivity as using time efficiently, is the valorized quality of adulthood (Hamdani, 2016).

Development. A large component of the literature review pertains to the notion of “development” and its reproduction of the linear life narrative. When referring to development, I am particularly interested in the underlying psychological assumptions (i.e., growth and change as consistent and systematic throughout the lifespan) (Vandenberg, 1993). Implicit in these assumptions are expectations and ideals of normality.

Normality. From a critical standpoint, “normality” is problematized to represent something that is typical or expected based on norms derived from measurements of populations of children (O’Dell, Brownlow & Bertilsdotter-Rosqvist, 2017). This writing is informed by the notion that the “normal child” is itself a product of history and culture at large—it is a social construction.

There are limited, conditional and restricted knowledges about the situations of normality through time (see O'Dell et al., 2017). All the while, understandings of universal, normal development are preserved in our everyday practices and institutions in the dominant culture of Western society.

Disability. “Disability” can be understood from a multitude of perspectives: from medicalized to social to political, as well as through a cultural lens. Briefly stated, the medicalized model of disability locates the “problem” of disability within the person; in this sense, disability is something that must be dealt with and fixed (Crow, 1996). On this view, as Erving Goffman (1986) states, disability “spoils” the being. Since the 1960s, however, there has been a paradigm shift in the understanding of disability due to political and legislative policies that aim to integrate people with disabilities as full citizens. With this comes the advent of the social model of disability, which functions to criticize society in its attempts—whether deliberate or as reflective of unexamined assumptions—to marginalize and exclude people with disabilities from full access to their surroundings (Shakespeare, 2014). The social model of disability emphasizes removing physical, attitudinal, communicational and environmental barriers to enable equality. Shifting perspectives, rooted in cultural studies, an analysis of disability as asserted by Garland-Thomson (2012), considers disability to be the body’s reaction over time to its environment; it is something that occurs as a person encounters the world and its innate features (i.e., time, space, and development). One may conceptualize such an understanding of disability as one’s body coming into conflict with one’s surroundings. Garland-Thomson (2012) refers to this as “the transformation of flesh as it encounters world” (p. 342). In this sense, disability is inherent to the human being, as we are all vulnerable and contingent upon time and the world at large. I argue that society needs to make a move from a medicalized understanding of disability (still ever-present, despite the social model of disability’s attempts) to a cultural understanding of disability—an understanding of disability that acknowledges our existential condition of precarity.

4. Thesis Organization

This thesis consists of five chapters. Chapter 1 has introduced the idea of our precarious existence and its mismatch with our dominant conception of time in the global north, key terms, and the thesis as a whole. In Chapter 2, I review the literature that has shaped this problem,

including how linear temporality has come to dominate and suppress other forms of temporality; I also examine the theory and key concepts (e.g., precarious existence, time/ temporality, development) that are relevant to my analysis. In Chapter 3, I describe the research design and methods that I used to collect, generate and analyze data to answer my research questions. I used a qualitative memoir analysis to explore parents' accounts of their experiences raising children with atypical temporal experiences. Chapter 4 presents my findings and Chapter 5 situates them within the context of existing literature and includes discussion of the implications of the findings, the limitations of my study, and future directions for research.

Chapter 2: Review of Relevant Literature and Concepts

In this chapter, I review some of the literature pertaining to how time and how our cultural relationship to time has come to be dominated by a linear, progressive orientation. The chapter is split into three parts. In the first section, I begin by introducing precarity as an existential problem. I then suggest that an adequate acknowledgement of precarity cannot take place without the consideration of time and its ontological and epistemological properties. From there, I discuss time as both being and becoming, as well as articulate the distinction between ontological time and society's organization around time. To conclude this section, I introduce linear time, the dominant epistemological construction of time that goes unquestioned due to its congruency to ontological time.

In the second portion of this chapter, I discuss the emergence of linear time. I revisit the advent of industrialization and enlightened thinking in the nineteenth century, arguing that it is here where contemporary Western society's dominant conception of time was transformed. I then discuss how the domination of linear time has continued to pervade the modern world, perpetuating the pervasive neoliberal agenda of how we see and "tool up" children. I deem developmental discourse, as grounded in developmental psychology, education and play, as a mechanism of reproduction for the normative and ideal trajectory of progress.

To conclude the review, I report on what happens when one is unable to meet the standards of linearity. I discuss the efforts of "curative time" to restore linear development. I also examine the segregation and removal of recognition that occurs when one is unable to keep "on time". I finish with an inquiry into the sidelines. How do people relate to time if they are unable to relate linearly? Is there generativity implicit in such insights? Here, Garland-Thomson's (2012) publication, "The case for conserving disability" as theoretical premise will be addressed in more detail.

1. Precarity and Time: Can't Have One Without the Other

1.1 Precarity as an existential problem

The Merriam-Webster dictionary defines precarity and its other forms of "precarious" and "precaritization" as "dependent on chance circumstances, unknown conditions, or uncertain developments" ("Precarious", 2022). It is a term used often in labour studies and economics to

connote lack of stable work and steady income deriving from capitalism's influence on the contemporary world (Lewchuk & Laflèche, 2016). In short, when one is said to possess precarious employment, their job lacks permanency, regulation and ultimately comfortability, as it can be taken from them at any time. Although the term is typically utilized within the context of the proletariat and political disciplinary perspectives, Grenier and colleagues (2020) appropriate the word to broaden the analysis of precarity from insecurity and unpredictability in work, to experiences of vulnerability and distress more generally. They argue that precarity is an experience of the human condition; it is a widespread structure of diffidence, weakness and potential suffering. In this sense, precarity is a common human vulnerability as our species is inherently contingent, and life truly does go on without assurances. Judith Butler (2015), a pioneer in cultural studies, notes that human beings suppress such desolation about the domains of our being through attempts to lead a self-sufficient and relatively organized existence. In saying this, Butler contends that we unconsciously ignore our shared common vulnerability (or precarity, if you will) through mutual and societal attempts to control our reality. This thesis has its impetus in such a notion, particularly because our shared possession of an uncertain future is revealed when we critically consider lessons from the COVID-19 pandemic, as well as increasing threats of climate change. How has our shared vulnerability stayed secret despite the ever-revealing threats to our humanity?

The COVID-19 pandemic, which scientists argue is on the pathway to the gradual emergence of endemic status (Herrero & Madzokere, 2021), has truly illuminated the unprecedented nature of our world. From March of 2020—and even earlier in some places—citizens of the planet experienced lockdowns, isolation and millions of deaths³. Suddenly, institutions of the Western world that were perceived as ordered and stable revealed cracks that were only known to exist for some. Mandatory government orders required people to stay home and stay away from others; schools, workplaces, facilities of leisure, retail and cuisine (among many others) were shut down with predictable yet shifting reopening timelines. “Fear, worry and stress are normal responses to perceived or real threats, and at times when we are faced with uncertainty or the unknown” reports the World Health Organization (2022, n.p). Based on this, it can be argued that—in addition to the immediate health impacts of the virus and the consequences of physical

³ See Rehman & Ahmad (2020) for an informative review on the structure and epidemiology of the disease.

isolation—it is the inability to come to terms with the length of the pandemic that has brought upon such melancholy throughout the nation. The difficulty in formulating and following a plan has occurred and our uncertain futures have been exposed.

A less immediate, but most definite serious indication of our precarity comes when we get wind of climate change and its effects on our environment. Climate change has been widely accepted by both the scientific and lay community—at times the political community as well—as a product of human activity that will have devastating consequences for all nations. In their policy brief from 2008, the Oxford Research Group reported three major indications of climate change: global average temperature increases⁴; rise in sea levels⁵; and altered weather patterns⁶. Global warming will cause a dramatic transformation of our world, with implications arising in the more frequent and severe weather we experience, higher incidences of illness and death rates, murkier air, higher wildlife extinction rates, as well as more acidic oceans (derived from a meta-analysis by Denchak, 2016). To add, in conjunction with glacial and ice sheet melting, the Intergovernmental Panel on Climate Change suggests that sea levels could rise up to a metre or more by the end of century (Warrick & Oerlemans, 2010). As the Oxford Research Group (2008) reports, “Just to put this in context, in Bangladesh for example, over 17 million people live at an elevation of less than one metre above sea level” (p. 5). Mass displacement of people, resource scarcity from regional variations and extremes is very much likely to result in the loss of infrastructure (Mitchell et al., 2010). The Oxford Research Group (2008) policy brief ends with a demand that global leaders, governments and non-governmental stakeholders rethink current approaches to mitigation, adaptation, and sustainability in order to increase our chances for the future. As global warming and climate change continue to wreak havoc, the foundation of society and life as we know it will shift and will ultimately become unsteady; things we depend upon now, such as habitable geographic locations, government aid, and security, may be unable to support such considerable changes to our surrounding environments.

⁴ Global warming is the result of human activity in burning fossil fuels and clearing forests, which has equated to an increased concentration of greenhouse gases in the earth’s atmosphere (Mitchell, Manabe, Meleshko, & Tokioka, 2010). This translates into more of the sun’s energy radiating onto earth thereby heightening the levels of carbon dioxide in our atmosphere, which ultimately increases the average temperature throughout the planet.

⁵ A rise in sea levels comes from the oceans absorption of increased heat (Warrick & Oerlemans, 2010).

⁶ Scientists predict that altered weather patterns, notably regional variations and extremes, may lead to resource scarcity and loss of infrastructure (Mitchell, et al., 2010).

To dissect how those in power across the globe maintain order and stability amidst the urgency of our uncertain futures, one must look to reigning ideology of neoliberalism in dominant Western cultures. Despite the ever-increasing foreshadowing of societal instability, Kittay (2020) argues that neoliberalism and its ideological valorizations promote security. When one is to be independent and self-sufficient, neoliberalism communicates that we have reasonable expectation that we can avoid the harms that this precariousness threatens. But, as Butler (2015) contends, it is not only the precariousness as individual persons that is revealed in times of social and economic deprivation, but also the failures and inequalities of socioeconomic and political institutions. Although we are all vulnerable to the exposition of what may happen, precarity is lived differentially, and that difference is affected by one's individuality—the socioeconomic and political inadequacies are often hidden (Butler, 2015). In this sense, collectively, precarity is not acknowledged—the burdens of dependency are displaced onto the individual (Tremain, 2021). When conceptualized this way, one may see the relationship between precarity and disability in that precariousness is an existential condition that is intensified by disability (i.e., the individual “identity”). The individualizing and maddening form of responsibility is not based on an ethos of solidarity that affirms mutual dependency, but rather on one's body navigating the world on their own. According to Kittay (2020), when a body is associated with dependency on the world, they are opened to fragility on multiple registers. Although we all depend on others to ensure our air is breathable and our water drinkable, cognitive, psychological, physical and sensory issues threaten one's ability to independently be secure. In arguing that prosthetics are an indication of our investments in future world habitability, Scuro (2017) states that the “built environment is a neoliberal complex of rigged demands and expectations, rendering precarity based on the ideology of Social Darwinism” (p.11). Put simply, neoliberalism results in the societal delusion of thinking that we are much more safe and secure in our lives than we are. Yet, when one is unable to match the ideals of neoliberalism, the precarity of their existence is more likely to be exposed. As Kittay (2020) asserts,

Situations may look precarious when we consider all the possibilities that can go wrong; still that precariousness need not affect our quality of life—again as long as we have reason to feel relatively secure that we can get what we need. [...] In disability, we

encounter more occasions where we face the possibility of losing the form of wellbeing we have achieved. (p.296)

How do these feelings affect the ill, the disabled, and other dependent individuals' futures? How does a greater exposure to precarity affect the ways in which one relates to and interacts with time—in other words, their temporality?

1.2 Time as inextricable to the context of life

Implicit in the notion of precarity is our state our existence within time. To be sure, time is itself an incredibly nuanced and complicated concept. In an effort to attain a comprehensive metaphysics of time, Marcello Oreste Fiocco (2017) posed the fundamental question “what is time?” As he progressed through his inquiry, he argued that “Time is the thing that makes change possible” (Fiocco, 2017, p. 56), accentuating the intimate relationship between time and change. In other words, change is the occurrence that strikes when an entity is one way and then the entity is another—an incompatible way, if you will. Underlying change are moments, which are naturally deemed temporal; when something occurs at one moment, then at another moment is incompatible to the first moment, that moment can be considered a distinct moment from the first. That said, time is the ontological core of the “temporal order of moments” (Fiocco, 2017, p. 57). One may think of the notion of “later than the present moment”, meaning a change from what was, or “earlier than the present moment”, meaning a preceding change to what is, to simplify such a complicated concept. In short, any moment, ontologically, is contingent on time: “the mark of existing in time is existing at a moment thereby poised to change” (Fiocco, 2017, p. 63). Accordingly, based on Fiocco’s (2017) contention, time can be viewed as a full structure in reality. Time is in the world; it enables change, and it facilitates development and deterioration. It is time that underlies the limited durability of one’s cells, where in one moment the miniature cell is one way and then in the next, incompatible (hence, change). Thus, time cannot be separated from context; it is an inextricable facet of the ways in which humanity exists, conducts and operates within the world (Compton-Lilly, 2013).

Because time is inextricable to context, ontologically, we are constrained by the processes of time as it manifests through biological aging; in such sense, we are always “becoming” (Uprichard, 2008). This does not suggest, however, that we are not always “being” as well. This is in stark contrast to the unresolved debates in childhood studies that conceive the concepts of

children “being” and “becoming” as mutually exclusive binaries (see Qvortrup, 1991; James and colleagues, 1998). In an effort to theorize children as both “being and becoming”, Emma Uprichard (2008) utilizes lessons from Ilya Prigogine, an internationally renowned physicist, to implicate temporality into childhood studies conversations. From a temporal standpoint, Prigogine postulates that the dynamics of time in the social world are always “being and becoming” (Uprichard, 2008). Similar to Fiocco’s (2017) assertions, Prigogine contends that time should be considered ontologically, as an intrinsic feature of change. He takes this further, however, by suggesting that time is also epistemological, in that it can be understood as a “marker” (Uprichard, 2008, p.307). In this regard, time is both internal and external to the entity itself. It is internal in the sense that a person must biologically age—that is an ontological property of being human (recall Fiocco’s assertion that time means change). It is external in the sense that individuals are situated within contexts that are organized around time, where knowledge is constructed around such a premise as fact. To clarify, take for example “childhood”; childhood marks the existence of being a child—ontologically, a child is a young human (internal), while epistemologically a child is situated in the space that precedes adulthood (external). In childhood, young people are allocated resources and graced with particular characteristics that mark them as distinct from the individuals situated within adulthood (i.e., ontologically, an older human). Thus, there is an interplay that posits the individual in such a temporal event—the interplay of ontology (internal facet of time) as well as epistemology (external facet of time). It is the chemistry between the different notions of time that is key to understanding our lived temporalities and their effect on our lives—one is constructed based on something that is inextricable to our existence. In short, epistemological time is founded on ontological time.

To expand, temporalities—the ways in which one relates to and interacts with time—are epistemological constructions of ontological time. To explicate this notion, the ways in which we have understood children, and the concept of “childhood”, have undergone significant alterations over the past three centuries. The Sociology of Childhood, for instance, argues that childhood is a sociological construct—there is a historicity of childhood: it is something that changes, is a non-constant and therefore, is not an essential condition (King, 2007). Implicit in this notion is the idea that childhood, age and—as I will argue throughout this work—time and temporality implicated within this context are socially constructed. Of course, we are ontologically bound by

the “arrow of time”—that is why “childhood” as a marker of time has always existed (childhood precedes adulthood). At the same time, the way in which thresholds are created between “child” and “adult”, for instance, are constructed within specific times and spaces. In saying this, I propose there is a difference between how we construct the notion of a “child” and actually being a child. To be sure, these constructions may have some impact on the child’s being, but that is not to say that the child is ontologically not a young human. To reduce such epistemological constructions would be considered an “epistemic fallacy” (Bhaskar, 1975).

A further context to consider in this regard relates to time as an inextricable feature of our reality, which we as humans interact with, complement, and ultimately construct. In recalling Bhaskar’s (1975) epistemic fallacy, how we construct the notion of time is not to be confused with time as change both internal and external to us. In this sense, one must seek ontological temporality and the ways in which we organize ourselves around time as separate entities. Time is not an illusion; on top of ontological time is constructed time: a child exists, but that child has also been constructed.

1.3 Linearity as the dominant conception of time

Despite time being an ever-present feature of our lives, the ways in which we perceive it and relate to it have undergone considerable shifts over the past three centuries. Take, for example, the concept of linear time, which has gradually supplanted alternative notions of temporality (more on this to come). Linear time, also referred to as “Aristotelian time” or “clock time” is conceptualized as abstract time that passes on infinitely into the future without reference to context, nature, nor human interaction (Rappleye & Komatsu, 2016). One may think of this concept as the “passage of time,” where we have experienced the past, live in the present and look to the future. It could be argued that, among other things, the primary channels of work, education, development and normative milestones contribute to the delivery of such a perception. All communicate a message to be internalized that development is premised on a particular temporality—a linear temporality—where actions in the present are evaluated in terms of their function for the future. To be further explicated, linear temporality, which may also be referred to as progressive time in this work, is the hegemonic conception of time in the dominant culture of the global north.

In tandem with the “arrow of time” metaphor, our prevailing understanding of time is very much oriented to the future. Empirically, this notion makes sense, as linear time is congruent to the ontological property of time (i.e., the temporal order of moments). Humans do not question linear temporality because it is perfectly logical. But what has happened in recent centuries is a privileging of the future, where the present seems to be swallowed up by futurity. It appears that individuals in a society premised on linear temporality appreciate the present only in terms of what it leads to—a particular kind of temporality, if you will. Socioeconomic and political institutions, which affect and are depended upon by the individual life, appear to privilege movement toward a particular endpoint and function to move individuals in this particular direction. Revisiting the aforementioned unresolved debate in childhood studies regarding the child as “being” or “becoming” (as noted by Uprichard, 2008), my work has impetus in the dominant culture of Western society’s attempt to negate the “being” of the person in favour of the “becoming” of the person to a valued endpoint; it is the child that is on its way to adulthood, or the person with the disability on the way to rehabilitation. Such an emphasis has been derived from the developmentalist discourse contributing to conceptions of childhood development, and the privileging of this particular discourse into common understandings of naturalized life course progression. Authors such as Brannen and O’Brien (1995), James and James (2004), James and Prout (1997), Jenks (1982, 1996) and Qvortup (1991, 1994) have long argued that from the moment a being is born, the concentration is on the future and who this being is to become. My objective is to show is that society values productive and contributive citizens, so institutions such as education and practices such as childrearing are all reflective of the type; children are presented with opportunities in the present that accord to the future. As well, this work seeks to disclose how those who are unable to live linearly (i.e., those who are unable to utilize their present for the acquisition of skills in the future) are temporally marginalized. In the remainder of this work, it is my intention to showcase the aforementioned implications of linear temporality. This will be achieved by looking at how development, education, play and childhood as mediated by institutions more generally, embody that linear temporality. I aspire to disclose some of the history of the emergence of linear temporality, the contemporary employment of linear temporality, and of course, the consequences of the hegemonic emphasis on living linearly.

One may wonder why such a fixation on the future has manifested. To answer such an inquiry, one must first look to the emergence of the constructed temporality in the Western world. People have not always abided by linear temporality—it was not until the nineteenth century that such a temporality became ubiquitous. The answer to the privileging of the future lies in the growing ideological transformation of the time. This will be disclosed in the following section.

2. Linearity as a Construction

2.1 Linear time is rooted in history

In the time before and in the time of the nineteenth century⁷, the ways in which people related to time (i.e., temporality) was very different from the ways in which we consider time today. It could be said that life was slower in the past. According to Baynton (2011), such an understanding has merit; the pace of life was considered “quotidian”⁸. In the context of labour, for example, self-determined methods of agrarian and cottage-based work provided people with their living (Paterson, 2020). People were unable to depend on mass-trading and “grocery shopping” to satisfy their hierarchy of needs. According to Hirschman and Mogford (2009), most people were only connected to the external world by way of horse drawn carriages—the fortunate ones were those connected to railroads or water. The isolation that was associated with transportation being so limited translated to a life of self- and familial sufficiency. Farming, agriculture, and the rural life required hard work, and this work was irregular, determined by patterns of nature. In such a sense, one can surmise that mechanical clocks were not depended upon; rather, time would be considered from the perspective of completing the task and finishing the job. Productivity was achieved when the task was finally complete and, of course, done well. Paterson (2020) adds that the body was also a source of temporality, as it mitigated both the extent and duration of the task undertaken. All members of the family were to contribute at any pace they could manage—it was about survival. All in all, temporality was conceived in such a way that clocks were not needed; task completion, the course of the day, the changing of the

⁷Some theorists posit that these processes were set in motion during the eighteenth century, while others argue these social and political-economic changes began occurring in the 1500s (see Squicciarini & Voigtländer, 2015)

⁸ Baynton (2011) suggests that such an alteration to temporality was grounded in an earlier belief system in which the world was considered an invention of sentient design, imbued with purpose. Prior to the catechism of scientific thought, people of the West believed that entities were created intentionally, and of course, for and with a purpose.

seasons, and nature's life cycles communicated the epistemological context of time (Paterson, 2020).

As many American workers continued to make their livelihoods through farming, others began to gain employment in manufacturing. Previously, small artisan manufacturers produced tools, furniture, building materials and other goods for local markets; they were supplemented by local grain mills and sawmills that used flowing rivers to power their machinery (Hirschman & Mogford, 2009). It was not until such workshops and forges began to be replaced by large factories in urban settings that things changed. These large factories engaged in mass production—mass production equated to a lower cost and simpler methods of creation. The emergence of industrial developments coincided with the rapid expansion of rail lines, the advent of commercial electricity, automobiles and telephones (Hirschman & Mogford, 2009); this resulted in goods being able to be transported to both rural and urban areas quickly. Of course, larger factories, increased manufacturing, and subsequent transportation required more labour; and thus, from 1880 to 1920, employment in the manufacturing sector expanded from 2.5 to 10 million workers⁹ (Hirschman & Mogford, 2009). Within these transforming workplaces, in opposing cottage-based production and task-oriented temporality, timekeepers oversaw uniformed workers. People were disciplined by time; production needed to move fast. It appeared that the movement of the mechanised factory floor as a whole became more important than the movement of the individual worker (Paterson, 2020). To make money, goods needed to be produced quickly; time and money were becoming increasingly equated. In line with theorists such as E.P. Thompson (1967), I propose that it is here where task-oriented time began to be supplanted by linear, clock time.

2.2 A shift to ideology... and to the dominant temporality

Evidently, the restructuring of time was exposed by the end of the 1800's (Baynton, 2011; Paterson, 2020; Hirschman & Mogford, 2009; Thompson, 1967). In 1875, William R. Greg wrote, "Beyond doubt, the most salient characteristic of life in this latter portion of the 19th century is its SPEED—what we may call its hurry, the rate at which we move, the high- pressure at which we work" (as quoted in Baynton, 2011, p. 48). In addition to the social and economic

⁹ Immigration also boomed during this time. See Rast (2012) *Why History (Still) Matters*.

world becoming more industrialized, scientific concepts were beginning to be applied to social questions. The teleological explanation of causation in the past, specified as the “function of its cause” ideology, began to be replaced by a worldview that placed hope in progress, and fear in decline, ideas rooted in the Enlightenment¹⁰ (Baynton, 2011). This coincides with the emergence of Darwin’s theory of natural selection (1838), where life was situated as an evolutionary competition (as cited by Vorzimmer, 1977). “Survival of the fittest” began to characterize the ideology of the society, Americans found themselves dragged into a competitive industrial society, and, according to Baynton (2011), they became participants in the “rat race” of life. It is clear that the emergence of such a temporality carries with it implicit lessons regarding how a person is to live and act in society.

And so, the nineteenth century brought with it an ideology that sought actions of the present as assessed in terms of achieving ends. Time was to be used well; Baynton (2011) coins this as “the gospel of efficiency”. The maxim “slow and steady wins the race” was quickly replaced by the adage “time is money”. Time became considered as being intentionally spent to shape the future (resulting from the Enlightenment and industrialization) as opposed to being passed and living in the present (the temporality of agrarian and quotidian times). Thus, this historical period transformed the dominant temporality by which individuals constructed their lives.

2.3 Linear time in the “modern”¹¹ era

Since its advent in the nineteenth century, linear time continues to remain the dominant conception of temporality in Western society. The ideals of using time “productively”, the adage “time is money”, class systems organized around “survival of the fittest” and humanity’s placement of hope in progress and fear in decline (Baynton, 2011) continue to characterize the ways in which we live our lives today. Neoliberalism—a multifaceted theory pertaining originally to economics and evolving into a sociopolitical ideology—is a fashionable example of how the historical roots of linear temporality continue to seep into our contemporary value systems (Bettache & Chiu, 2019). Neoliberalism began as a set of economic principles

¹⁰ In Schmidt’s (1996) translation of Kant, “Have the courage to use your own understanding” is deemed the motto of the Enlightenment period (17th-18th century). Kant advises those interested in Enlightened thinking to emerge from self-imposed immaturity to a possession of reasoning, rationality and scientific knowledge.

¹¹ The author contemplates the use of “modern” to describe our contemporary world. Should Western society be considered modern or post-modern? This question is outside the scope of this paper.

championing values such as competition and entrepreneurship; indispensable was the presence of a culturally shared belief in self-governance. As time has passed, neoliberalism has developed into a psychological axiom whose principles we are advised to live by (Bettache & Chiu, 2019). The psychological principles inherent to this ideology state that independence is a universal human desire, inequality inspires agency, and productivity, innovation and wealth creation should be privileged capacities (Bettache & Chiu, 2019). According to Azevedo, Jost and Rothmund (2019), in the United States, people who subscribe to neoliberal beliefs tend to retain personal qualities of self-interest, conceit, support the social dominance course and compete for the sake of evading social disapproval. In short, the proliferation of a culture fortified by characteristics of productivity and efficiency holds individuals responsible for fixing their own problems in order to lead independent and productive lives. Such a feature of society lends itself well to images of the ideal development, where one is to be responsible for their own being and space in the world.

Evidently, neoliberalism—arguably the most pervasive ideology characteristic of the global north—is a proponent of a particular type of being. This *ideal* human is one who is able to self-govern, is independent, is dynamic and innovative, and competes to be a contender for the top spot. Like history, perceived from the Enlightened perspective as something that is linear, advancing and cumulatively progressive, the ideal human is to be the same. Recall during agrarian times when all, regardless of ability, helped contribute to the method of production, with the duration and extent of efforts mediated by the body only, and not society. Over time, age—both an inevitable facet of ontological time as well as an epistemological marker—has become an important variable around which society could organize itself (Hutchison, 2005). Many social institutions are structured, in part, around age—the age for beginning school, the age in which one is allowed to vote, the age for retirement, and so on. The emphasis on age has allowed for a trajectory to be set for the construction of the ideal human (as reflective of the ideals of neoliberalism). When one is young, development is organized to provide one with the skills and acquisitions needed for later life; in a neoliberal society, these skills include being productive, using time well, and so on. To put this ideal into context, children up to sixteen are required to attend compulsory education as it is conceptualized as an investment in their future (Oreopoulos, 2006). In the context of adults, the economic structure of the global north perceives productivity as the only way to increase total wealth, so people striving for independence—characteristic of

neoliberalism—must work (Bettache & Chiu, 2019). Both of these “duties,” if you will, seek actions in the present as mechanisms for a productive future—children go to school to gain abilities to work, and adults work to compete in the “rat race” of life, working to get ahead of the other. When conceptualizing an individual’s place in the neoliberal society, one may be illuminated to the palpable consequences of a particular type of temporality. The linear temporality inherent in the psychological axiom of neoliberalism instrumentalizes the present to bring about certain desired outcomes. If the aim of this work is to attempt to understand how the future is foregrounded vis-à-vis the present, one must pay close attention to the connection between becoming and desired outcome.

2.4 The ideal trajectory along the linear life

In order to achieve such a valorized adulthood marked by independence, productivity and a contribution to society (Hamdani, 2016), prevailing discourses of temporality presume a standard and projected evolution through essential tasks and achievements from childhood to adulthood. This is reflected through the term “development,” which assumes that accomplishing such objectives will adequately prepare children for what is to come as they voyage through ontological time to their epistemological “endpoint” (i.e., productive adulthood). Such a progression along the ideal trajectory is referred to as the “linear life narrative” (Fisher & Goodley, 2007).

The linear life narrative tasks children with a heavy burden of responsibility: they are expected to achieve the milestones of normal development as defined by the apparent norms and aptitudes of adult life in the surrounding culture (Priestly, 2003). The trope of the linear life, from a temporal standpoint, deems those who are young as responsible for a transition to a space of ideal adulthood, possessing meaningful temporal experience—temporal experience that is skillful and reflective of the neoliberal culture at large. The acquisition of such skills and advancements is normal and standardized. In this sense, childhood, enveloped in the developmental ideology, is seen as a mechanism for the future. Children are “candidates” for adult life, and parents and schools function as the responsible agents in preparing them for the future (Kizel, 2016). This “ideology of adulthood” is rooted in linearity; the narrative it is embedded within perceives childhood as a stage of immaturity, dependence and incompleteness, and adulthood as its opposite—the end of incapacity (Kennedy, 2006). In sum, it is the linear life

narrative that deems actions in the present to be evaluated “in terms of the efficiency of means in achieving ends” (Siegel, 1988, p. 130). In the following subsection, I will discuss the linear life narrative and its infusion into normative child development, education and even children’s play. Embedded in such a perspective is a temporality that is oriented to the future in efforts that often negate the present as well those who are unable to achieve the “norm”.

2.4.1 The influence of developmental psychology

As mentioned, the concept of normative development is principal to our everyday understandings and perceptions of children, especially in relation to temporality and the linear life narrative. This notion is couched within the academic discipline of “developmental psychology,” defined as the branch of psychology concerned with when and how we change over time (Kail, Liebert & Wicks-Nelson, 1993). Developmental psychology looks at the trajectories of humans—the development of personality, sense of self, language acquisition and communication abilities. Kail and colleagues (1993) note that developmental psychologists study people of all ages in an attempt to understand systematic developmental continuity. Inherent to the term “systematic” are notions of structure, expectation, order and standards—normativity, if you will. In line with this, in their work on transgressive childhoods, O’Dell and colleagues (2017) argue that many of the dominant frameworks in developmental psychology development as a universal, ongoing buildup of skills and abilities across time. The term “universal” has resulted in prevailing discourses of development and what expected progression should look like¹². In accordance with this, from the perspective of time, the linear life narrative can be seen “as a series of developmental levels and stages,” which all must proceed through (Compton-Lilly, 2013, p.85).

To summarize, the linear life narrative and developmental psychology implicate each other in the supposition of child rearing. Children are expected to meet and achieve their developmental “stage” at the correct chronological age; due to the influence of conventionalized and normalized cut-off points for developmental milestones, those who are “off-time” are said to be deviating from the norm and thus are subject to diagnosis and repair. The developmental trajectory creates a link between the past, present and future and such a construction becomes common sense,

¹² This is not to say that developmental psychologists conceive development without reference to culture. See Keith (2011).

second nature and unquestioned ground for thinking about development, which according to O'Dell and colleagues (2017), appears as natural and obvious. Individuals are supposed to follow an even course from birth to old age, according to stage models of development.

Related to ideas presented earlier, cultural priorities of Western society, dating back to the end of the nineteenth century, have become embedded within the ideals of development. Adults (i.e., those who have come out of the epistemological marker of “childhood”) are to be rational, independent, and of course, productive with their time. Recall Siegel (1998) who states that the linear life narrative deems actions in the present as evaluated “in terms of the efficiency of means in achieving ends” (p. 130). It is always about getting back on track with expected life course experiences, such as education, employment and retirement (Compton-Lilly, 2013). In short, the historical roots of linear temporality seep into our contemporary value systems (i.e., neoliberalism) and become buried and seemingly unquestioned yet ever-present features of our reality. This begins in infancy where already the present is being instrumentalized for gain later, in the future, and continues on and on until one has seemingly reached the endpoint of productive and independent adult.

2.4.2 Education as a mechanism of the hegemony

Education—an institution premised on a particular temporality and conception of developmentalism—is another mechanism of hegemonic linear temporality. Social institutions assist young people in progressing through ideal trajectories; these institutions are informed by the prominent ideology of the culture. Education, like many social institutions, uses age as a means of credibility (Kizel, 2016). This is a temporal manifestation. Kizel (2016) notes that the traditional classroom is a place of preparation for the future, with students being conceptualized as contenders for adult life. This aligns with a point established earlier pertaining to Western cultural aspirations and their attempts to formulate valued adults as those who are autonomous, rational and productive with their time (dating back to nineteenth century ideals, as per Baynton, 2011). Based on such principles, it appears that the ultimate goal of schooling is to move its participants from dependence to independence (Hamdani, 2016). Thus, education is not a place of student-centered improvisation and self-direction in real time; it is a pre-engineered structure that is orderly, organized and, of course, goal (future) oriented.

Similar to ideas as embedded in developmental psychology, in relation to schooling and grading, Ontario students are evaluated based on curriculum expectations as dictated by the provincially run Ministry of Education. In order to proceed to the next grade, students must satisfy both “Overall Expectations” and “Specific Expectations”. The language associated with such expectations state, “By the end of grade [blank], students will...” (Ontario Ministry of Education, 2016). In this sense, students enrolled in public education¹³ are said to be on the pathway to the end of incapacity and the overcoming of a deficit condition (Kennedy, 2006). Education is a means of linearity where one is summoned to develop according to a systematic plan to arrive at a known endpoint. In this sense, temporally, the child is established as an enigma that must be “assisted, aided and abetted” (Kizel, 2016, p.10). Without such aid, the child will resume within their marginalized and under-valued position, as they are unable to achieve such expectations required to thrive in such a linear life.

In line with authors such as Liebel (2004), Crafter et al. (2009), and Burman (2008), O’Dell and colleagues (2018) bring up an interesting discussion regarding children’s engagement in work as opposed to education. They note that children’s work lies at the margins of normative childhood due to particular Western ideas about children as distinct from adults. According to Burman (2008), national and international policy which frames the debate about working children conceptualize childhood as a period of vulnerability that requires protection and supervision from adults. In this sense, work is defined as part of the adult world and opposes schooling and education, central aspects of the normative childhood. There are developmental assumptions here, in addition to the argument of the highly contested notion of childhood innocence¹⁴, that posit that children must seek out expert help to ensure favourable outcomes in the future (Fisher & Goodley, 2007). Temporally, they are not ready, according to the linear life narrative; they are still “becoming.” From this perspective, the only labour children should be engaging in is education (i.e., academic labour) and play.

2.4.3 Play as instrumental

¹³ It is important to note that self- determined learning environments exist, for which learning is considered as taking place therein, opposing traditional methods of future- oriented skill acquisition. See Kizel (2016).

¹⁴ Childhood innocence has a deep and disturbing racial history, with children of colour as disproportionately caught in the criminal justice system. See Bernstein (2011) and Fass (2013) who argue about the privilege of childhood innocence.

Another example of the entrenchment of linear temporality pertains to functionalist accounts of play. As a verb, “to play” means to “engage in activity for enjoyment and recreation rather than a serious or practical purpose”; as a noun, “play” is defined as an “activity engaged in for enjoyment and recreation, especially by children” (“Play”, Merriam-Webster, 2022). However, according to Goodley and Runswick-Cole (2010), this dictionary definition, which posits play as something that is not practical nor serious, does not necessarily hold true—particularly in the modern age. According to the authors, in recent years, it appears that the intrinsic value of play has been obscured by adults seeking to focus on its instrumental value. A functionalist account of play acknowledges the many benefits of play in children: in addition to the development of skills through play, such as communication abilities, problem solving aptitudes, imagination and muscle control physical development, play also helps children grow physically, socially, emotionally and intellectually (Claughton, 2015). In this sense, play can be considered productive. When play is conceptualized as productive, it sustains the belief that the conclusion of play can be predicted (Øksnes, 2013). If Siegel (1998) is correct in his perception of actions in the present as assessed as means in achieving ends, then, taken critically, mandated play is children’s work for the future. Øksnes (2013) terms this as the “play as progress” ideology, where the focus is on the benefits and positive outcomes of play over and above the act of purposeless and pleasurable play.

Similar to normative benchmarks and milestones, when play is instrumentalized and degraded to a didactical tool (Øksnes, 2013), adults may see to regulating and controlling play. Play is to be seen as a tool to develop skills, over and above play as an act of naturalness and fun. In this sense, play may also become an enfranchised culture of judgement, where actions of play are assessed in terms of “good” and “correct” (Øksnes, 2013). When the quality of play is evaluated, then a level of achievement is set¹⁵; this threatens the spontaneity and intrinsic value of play (Goodley & Runswick-Cole, 2010). Not only that, but when one fails to play “properly” one is pushed into a category of not developing appropriately. Such a championing of the world of play particularly affects disabled children as the link between play and development as well as the link between play and normality override the disabled child’s right to play. Although

¹⁵ I reference Mildred Parten and her stages of play that children progress through. It is interesting because the theory is so embedded with a dependence on chronological age and linear temporality. Not to mention, it positions play as something that is essential and not “frivolous” (as cited by Rymanowicz, 2015).

disabled children's play is problematized based on a temporality that privileges the future, perhaps there is opportunity as disabled children's play might open up possibilities for rethinking play more generally—I aim to explore this idea further.

My objective has been to display how normativity is embedded within the linear life narrative and linear temporality more generally. I discussed how developmental psychology as an academic discipline has resulted in the advent of ideal trajectories and how these normative milestones are implicit in institutions of childhood. I went further by discussing how play has been affected by adult colonisation with a transformation from it being spontaneous to functional. A population which I have not discussed much are those who are considered “non-normative”. From here, I will be committing myself to a discussion of what happens when one transgresses from the benchmark, whether developmentally, at school or in play. I will revisit all three institutionalized mechanisms with the intent to showcase that it is never the linear model that gets dismissed; rather it is those who do not fit within the particular linear narrative that are marginalized, excluded and de-valued.

3. How Time Matters

3.1 How linear time affects those who are “off-time”

Just as humans experience precarity in highly singular ways, we experience relations with time in vastly peculiar ways. Again, time consists of the interplay of both “being” (subject to society's hegemonic temporality) as well as “becoming” (the ontological property of being human). So, although we all follow the same biological trajectory in ageing, the ways in which temporality affects our lives are different. It is important to bear in mind that developmental psychology's explicit emphasis on normative milestones and categorization based on chronological age involves a temporality that presumes children develop according to an even course. It is the temporality that frames development in this way. But what happens when one is unable to match the conventionalized milestones and benchmarks of dominant developmentalist accounts? What happens when one is “off time”? Below, I consider the implications of this temporality for disabled children.

Goodley, Runswick-Cole and Liddiard (2016) demonstrate how the construction of development as progression “reckons” on our lives by illuminating something called “the red

book”. In England, this book is given to all new carers of children; it charts the measurements of a child’s development and health from birth until they arrive at school age. Parents of children born with Down syndrome receive a unique insert that describes measures of the typically developing child with an additional twenty-first chromosome, essentially dictating what their child should be showing/doing/being at a particular age. Goodley and colleagues (2016) note that the attachment is very similar to the information in the traditional book, the only caveat being the “slower” pace of progression. Clearly, the “red book” maintains development as a singular, advancing and aggregate move through time; also, it depicts children with Down syndrome as needing to follow the same path as “normal” children but at a different pace (Goodley et. al, 2016). Simply delaying the benchmarks and milestones puts these children in an untellable situation: it does not respond to their difference. It is the pervasiveness of linear temporality that underlies this approach, with the implications for those who do not measure up. A temporality that is premised on progression imposes its mould on society in a way that does not recognize the diversity of the individual. It insinuates itself into people’s lives in a way that does not reflect alternative paths of development. In short, linear temporality imposes a singularity. When someone is unable to relate to the benchmarks as defined by the dominant developmental discourse, or even this “red book” for instance, the linear temporal model simply is unable to recognize that diversity.

As noted earlier, those who deviate from the benchmark are perceived as standing outside of the norm. From a temporal standpoint, the child’s biological age is not matching the necessary developmental age in a particular domain—they are “out of sync” from the norm (Landsman, 2003). It is here where the biomedical model would introduce therapy to assist the child to get back on track (the track being the gradual, accumulative procurement of skills through time for adulthood). It is the diagnosis that signals the lack of conformity with developmental time that allows the attempts to assimilate difference to take place (Fernandes & Robertson, 2019). Consistent with the scenario presented above regarding the child with Down syndrome, that child is still expected to achieve the same milestones as their typically developing peers, except at a slower pace (assimilation of difference). Alison Kafer (2013) refers to this as “curative time,” where there is an attempt to reassert linear development from a dependent childhood to independent adulthood. In other words, therapy and other biomedical efforts assume correction and normalization and pathologize malfunctions to existing norms. This reveals the power of

linear time and its infiltration into our consciousness; as Kafer (2013) states, western cultural discourses are unable to project a life where one is off track or “off time” and still able to be a valued member of society. The strength and endurance of linear time does not only have implications for the children, of course, but also the parents. When linear temporality and its manifestations present a narrative that does not conform to one’s life, it is almost as if time works against you (Fernandes & Robertson, 2019).

To further explicate the “reckoning” of linear time, I offer an example in the context of education. In their interviews with parents of children with complex disabilities in the United States, Nespor, Hicks and Fall (2019) imply that the temporal organization of the school produces a yearly “clearance” of the student’s past; once students have progressed into the next grade, the students’ actions and accomplishments of the year prior are erased. This is because education is constructed as temporally bound—students are bound to subjects, periods, terms and the school year. Teachers do not have access to children’s lives outside of those temporal bounds—without effort on behalf of the teacher, there is a difficulty in accessing the context of children’s biographical lives. In this sense, the classroom is the thief of biographical identities and the larger contexts of children’s lives (Nespor, Hicks & Fall, 2019). This results in a sort of discontinuity, where the child is framed as separate from the past and present—an alternative temporality, if you will. Of course, because the curriculum is structured to produce citizens with particular skills, there is still evidence of the pervasiveness of linear temporality, as argued throughout this work. The purpose of the year is to build for the next and the units are bound—once the period is over, students move on to the next subject; once the year is over, students move to the next grade. In this structure premised on a particular temporality, as opposed to seeing children in the context of their life story, children are seen as cases, not individuals (Nespor, Hicks & Fall, 2019). An interesting idea elicited by Nespor, Hicks and Fall (2019) pertains to the marginalization of students who would benefit from an alternative temporal relation, students who have transgressed from normative temporality¹⁶. The authors provide an anecdote of students who are unable to communicate orally—these individuals communicate by ways of motions, gestures and other modes of exchange that require intricate interpretations and close “bodily” consideration. In order for mutual understanding and alternative communication

¹⁶ I use this term strategically to reference past discussions of transgressions from milestones. This non-verbal child was unable to meet the milestone of oral pronunciation as dictated by theories of developmental psychology.

to take place, one must go beyond the existing temporal bounds of the school to invest time in learning about the child; perhaps the teacher spends more time observing and interacting with the child prior to their movement into the classroom. The authors argue that, by weakening their temporal boundaries, educators may attain richer representations of children. Unfortunately, however, Nespor, Hicks and Fall (2019) report that this is not how the schooling system currently functions. The barriers associated with an alteration to temporal infrastructure (i.e., the school year) are “integral to the multiple activity systems constitutive of the institution” (p.382). Hence, the disabling effects of the construction of the school are extremely difficult to remedy; or, in the context of temporality, they expose how temporalities can work against you. In short, temporalities matter! They capture the underlying assumptions that we have—they are buried yet are able to determine the decisions and actions we make and take. They can shape children’s experiences and do injustices to them: the fact that school is designed to be temporally bounded by age/grade/year is just another way of showing how time can impact people’s lives in both positive and negative ways.

The reckoning of linear time on play has already been unveiled. Play is utilized as a function of development rather than an act of spontaneity and naturalness; this is a result of the temporal ideology of adulthood. Recall from the previous section, when instrumentalized play was perceived as a naturalised culture of judgement, where actions of play were to be assessed in terms of “good” and “correct” (Øksnes, 2013). It was mentioned that when the quality of play is evaluated, then a level of achievement is set with an inherent value judgement attached. Children are then pressed to play “properly”. According to Goodley and Runswick-Cole (2010), this expectation unequivocally pertains to children with exceptional needs. The authors argue that play allows professionals to separate “able” children from “disabled” children; children who play “normally” meet the standard and are graced with the value, while children who do not are considered to be inferior (Claughton, 2015). In this sense, Claughton (2015) terms play as an “able bodied” concept (p.95). To clarify, in a meta-analysis of studies on play for disabled children, Brodin (2005) found that in most of the studies, children with profound disabilities were reported as not functioning according to recognized standards of play. If so, a discourse is developing that posits that the “disabled child’s play is either generally lacking or specific to their diagnosis, if they can even play at all (Goodley & Runswick-Cole, 2010, p. 504). On the other side of the coin, play for disabled children can also function as a mechanism of therapeutic

intervention (Goodley & Runswick-Cole, 2010). As mentioned by Øksnes (2013), when play is to be instrumentalized and reduced to a tool for something else, it is no longer play. When it is goal oriented and utilized as a process of educative acquisition, this is a means of “curative time” (Kafer, 2013). The effort to reassert linear development is unveiled when deviations to existing norms are pathologized.

In each facet discussed above, there are individuals who are unable to meet the standards of linear time. Despite the challenge and the opportunity to rethink temporality, when confronted with difference, the strength of the linear model remains intact. As Kafer (2013) notes, western cultural discourses are unable to project a life where one is “off time” and still able to be a valued member of society. Thus, these individuals who have veered from the linear life narrative track are excluded from normative and valued trajectories. If they are unable to become a productive, valued adult (the endpoint of said linearity), then they are excluded from the linear life narrative and the dominant life transitions and trajectories.

3.2 Temporal segregation (and eugenic logic)

Temporal segregation often comes as a result of a diagnosis of being “out of sync with time” or developmentally delayed from the norm (Nespor, Hicks, & Fall, 2009). In his attempt to develop an understanding of “communication disablement”, Paterson (2020) introduces the phrase, “choreography of everyday life”. From this perspective, choreography pertains to the junction between “embodied action, space and time” (p.207). Paterson (2020) refers to this choreography of everyday life as being contextual—it emphasizes the importance of socially coded movements and symbols in negotiating and altering everyday exchanges. Within these encounters comes communicative capital, provided one is able to comply correctly to the choreography at hand. Said differently, the everyday world requires individuals to mediate social, spatial and temporal encounters. If done correctly, as per the culture and sociality at hand, then one is afforded capital, or *value*. If encounters are mediated incorrectly, then estrangement and marginalization may be produced (Paterson, 2020). This can also be referred to as temporal segregation (Nespor, Hicks & Fall, 2009). When individuals with speech difficulties, for example, are unable to keep “in time” with the normative tempo of communication, they are subject to alienation from the prevalent choreography of everyday life, which privileges speedy and efficient communication (Paterson, 2020). Perhaps the listener perceives their alternative

ways of communicating as too slow, thereby conceptualizing their attempt at communication as failed. From there, the individual with the atypical temporal experience is outcast and excluded. They are granted no communicative capital, simply because the choreography of communication does not reflect the bodily position of people who are off time.

In this sense, temporal norms are ableist. In the book, *Manifestos for the Future of Critical Disability Studies*, Ellis, Garland-Thomson, Kent and Robertson (2019) define ableism as “Systems of oppression comprised of beliefs, values and practices that create and reinforce youthfulness and able-bodiedness/ able-mindedness as ideals, thereby casting old age and disability as devalued states of being” (p. xix). Implicit in such a definition is a particular rendering of valued temporality versus unvalued temporality. Those who are able to fit themselves into the standard trajectory of treasured development (i.e., non-disabled children) are afforded grace; those who are unable to match to the imagined ideal trajectory (i.e., those who are dependent—the antonym of productive adulthood) are estranged and marginalized. The oppressive nature of linear temporality is truly striking when it comes to people whose form deviates from the standard (i.e., people with disabilities).

This temporal segregation of individuals with disabilities has its roots in eugenic logic. In his work entitled, *Essays in Eugenics* (1909), Francis Galton—the pioneer of eugenic thinking—essentially stated that society would be improved if the more intelligent individuals outbred the less intelligent individuals. In this sense, Galton believed society should be organized into a hierarchy centered on intellect, with lawbreakers and idlers on one side and entrepreneurial types on the other (with a sizeable quantity of mediocrity between). George Estreich (2019) clarifies such a concept by stating, “Deploying the metaphor of an alphabet, Galton argued ... that citizens could be divided into classes A through X ...; that those at one end of the scale were, in every sense, worth more and should be encouraged to breed, while [those on the other] discouraged” (p. 14). Although we do not employ Galton’s assertions to divide citizens into discernable classes contemporarily, we still place extravagant value on intellect and, as this work has argued, normative development to reach a state of desired skills and intelligence. Because society continues to devalue deviations from a normative trajectory to an ideal endpoint, Galton’s framing of an idyllic hierarchy fits well into the dominant linear temporal framework. Similar to the axioms inherent in eugenic thinking, the linear temporal framework endures

through its imposition of a singularity on society (i.e., “at this age this person should be able to do this”). There are palpable consequences of temporality: if one is unable to match the benchmark or milestone, they are pathologized and their future is troubled. In short, both linearity and eugenic thinking are entrenched in an ideology that posits that the world would be better without difference, and by the same coin, without disability¹⁷.

Eugenic logic is deeply rooted in dominant, medicalized conceptions of disability. When disability is said to confer pain, suffering, functional limitation, dependence and social stigma, it is cast as a state of being that no one desires to occupy. In a society that devalues disabled embodiment, a discourse is constructed that states that when one enters into disability, they are immediately disqualified from the privileged position of the non-disabled. Using Mitchell and Snyder’s (2003) “disability as disqualification”¹⁸ as a frame of reference, society has separated those who are able and disabled both spatially and temporally, even with the advent of the prevailing critical disability discourse. This is because, even with the social and political traction since the 1960s¹⁹, the medical understandings of disability as “impairment, restriction, dysfunctionality, abnormality and exclusion” (p. 341) are still relied upon in existing dialogues. The developmental trajectory, and its inherent linear temporality, still requires humans to work to attain the desired neoliberal adulted endpoint. Normality requires people to develop as per the standard; transgressions are pathologized and progression should be standard and ordered. In this sense, the eugenic logic that argues for improvements to the social order is the same logic implicit in linear temporality. The intent of linear temporality is to gain skills in order to negotiate, compete and ultimately master the “choreography” of everyday life (Paterson, 2020). Those who are unable to enter and compete in the encounter, possessing not enough capital, are then excluded to the sidelines of the everyday world, willfully restricted from the linear life.

¹⁷ One would be remiss in not highlighting the link between racialization and temporality, premised on a eugenic philosophy of imagined superiority. Because the main objective of eugenic science was to “advance” the human race, eugenic scientists such as Thomas Jefferson, James Lawrence Cabell and Paul Brandon Barringer deemed African American heritable characteristics as “undesirable”, where one drop of African American blood was said to restrict a person of colour to life under a shroud (Dorr & Lambardo, 2008). These ideologies contributed both directly and indirectly to ethically disdainful laws and policies forged on maintaining a culture of white supremacy and contemptuous futures for African Americans (Reynolds, 2020; Lambardo, 2011).

¹⁸ Mitchell and Snyder are critical disability theorists; when they confer that disability is disqualification, they are not stating that disability is inherently problematic—they are stating how disability works in a society that devalues disabled people.

¹⁹ See the Americans with Disabilities Act of 1990 and 2009 and the United Nations Convention on the Rights of People with Disabilities.

3.3 Alternative temporalities arise from the exclusion from linearity

Although linear temporality has seemingly monopolized the ways in which we interact and pass-through time in Western society, alternative temporalities do exist. Take, for example, an individual with a disability, whose body has come into conflict with the world, normality, and the “choreography” of everyday life. Their relation to the future deviates from that of the dominant developmental narrative. Because they are temporally segregated from a society that praises linearity and future orientation, the ways in which they interact with the world may suggest an alternative temporal logic, perhaps one that does not privilege the future over the present. In what follows, I consider this issue of alternative temporalities in more detail, drawing on the work of several scholars who challenge dominant ways of thinking about time.

Judith Halberstam’s (2003) work seeks to invert and displace linear heterosexual/heteronormative timelines. Halberstam (2003) argues that queer uses of time and space flourish in opposition to the institutions of family, heterosexuality and reproduction in the dominant culture. Because the participants of queer subcultures must imagine their futures according to logics that lie outside of traditional forward-moving narratives of birth, marriage, reproduction and death, they inevitably produce alternative temporalities—temporalities that are constituted by their difference from conventional imperatives of time. In a related vein, Kathryn Bond Stockton’s (2009) work in *The Queer Child, or Growing Sideways in the Twentieth Century* helps us to understand how and why these alternative temporalities unfold. According to Stockton, the ways in which one understands growth and maturation are premised on linear concepts of development that many queer people do not experience—they mention that queer lives are often notable for their lack of “chrononormativity”. Stockton argues that because queer children often do not make sense of their desires and identity until they are older, they were often unable to occupy the normal reproductive trajectories and cultural ideals during their childhood. In this sense, when they were children, they were considered like ghosts—people unable to corporeally inhabit who they were to come to be (Stockton, 2009). Hannah Dyer (2017) takes this concept further when discussing the proliferation of debates in queer theory regarding the status of the child in relation to futurity. What is interesting about their work is the insistence on removing the constraining rhetoric of childhood innocence that seeks to invalidate the child’s potential queer desires—suggesting an alternative temporality in and of itself, one that

exposes the traces of colonialism and trans-Atlantic slavery on dominant conceptions of temporality. Dyer (2017) argues that it is not right to privilege adult theories of childhood, “compelled by our adult affective, remembered and unconscious experiences with education, family, and sexuality and underwritten by histories of race” (p. 300). In this sense, a queer future of childhood studies is yet to be exposed.

Evidently, temporality is addressed in different ways by different scholars. Although illustrated diversely, what each scholar has in common is an undoing of the dominant, linear temporality and a consideration of an alternative conception of time that implicates how different people interact with and see time in the world. My research falls in line with this important work, as I seek to question dominant structures of time and how linearity affects disabled children and their families. This intent falls in line with Paterson (2020), who looked at communication disablement from the perspective of a person with a disability in speech. Paterson argued that the temporal mediation of the everyday world—deemed “essentially ‘hidden’” (p. 207)—impacts disabled people, compromising their ability to participate in everyday encounters due to the “norms of negotiation that structure the choreography of communication” (p. 216). He concludes with a suggestion that ingrained, ableist norms and discourses relating to the signification of effective communication need to be dismantled. I interpret this as a call for an examination into time and how it matters and can affect each and every one of us (i.e., time can work for you or against you). Although Paterson did not explicitly note the alternative temporalities that individuals with speech disabilities may experience, he is suggesting that alternative temporalities do indeed exist.

In the next several decades of environmental, economic, political, cultural and technological upheaval, the precariousness of our existence is sure to be revealed. I have attempted to show how a temporality premised on progression and linearity has pervaded modern, neoliberal society and how this particular rendering of temporality does not align with our existential precarity. Consistent with the efforts of scholars such as Halberstam (2003), Stockton (2009), Dyer (2017) and Paterson (2020), who have all endeavored to go beyond the dominant framing of time, I now attempt to upset the dominant temporality by disclosing alternative temporalities as expressed by disabled people and their families. I aim to show that there are other ways to engage with time—ways that need not necessarily privilege the future. That said, this work is

grounded in the notion that it is precisely in encountering alternative ways of interacting and relating to time that possibilities may be disclosed for all. As noted earlier, this accords with Garland-Thomson's (2012) reflections on disability as a narrative, epistemic, and ethical resource. The linear temporal framework is not the only framework in existence for conceiving time, and experiences garnered from disability may help to disclose these temporal possibilities.

In saying this, I propose: Can the disclosure of alternative temporalities provide a wider range of options for thinking about time? Furthermore, can disability function as a resource (whether ethically, epistemically or existentially) for rethinking time, our being in the world, and the ways we approach one another?

4. Theoretical Grounding

4.1 Conserving disability

As theoretical footing, this research intends to employ Rosemarie Garland-Thomson's (2012) counter eugenic assertion that disability is generative. In keeping with the notion of conserving disability rather than eliminating disability, my objective is to showcase the generativity of alternative ways of being in the world, given that alternative temporalities may function as a resource for the wider society. In this sense, disabled perspectives will be utilized and employed as epistemological resources in the potentiality of their insights for others. Such a cultural analysis of disability runs counter to current medicalized, social, and political frameworks of disability, which continue to denote it as indication of some kind of lack of capacity, whether physical, structural, or functional (Garland-Thomson, 2012). Similar to research by Straus (2013) and Bauman and Murray (2010), in this work, disability is framed as something that is to be preserved; this work seeks to bring forward the gain disability offers to the community.

As mentioned, the theoretical grounding for this work comes specifically from Garland-Thomson's (2012) article, "The case for conserving disability, "; in which Garland-Thomson considers the question of why the world might want to keep alive or "preserve"²⁰ disability in the human condition. She argues that "disability generates circuits of meaning-making in the world" (p. 344) and she presents three ways in which disability functions as a resource. Each resource

²⁰ Garland-Thomson (2012) strategically uses the terms "preserve" and "conserve" disability over "protect" disability to distinguish the sturdiness of disability rather than its fragility. She is offering a perspective of disability as one that is a resource rather than a liability.

reflects counter-eugenic arguments for disability conservation: disability as a narrative, epistemic and ethical resource. Her intention is to present what the world would miss besides the individuals themselves if disability is rid from the world. In the following subsections, I will be summarizing Garland-Thomson's (2012) argument and counter eugenic logic for the conservation of disability in order to address some of the ways in which disability functions as a resource. This will serve as a foundation for my subsequent claim that one of the ways disability can function as a resource is to open up alternative temporalities that can help the dominant culture of the global north reimagine our relationship with time and, by implication, with others.

4.1.1 Disability as narrative resource

Garland-Thomson (2012) begins her taxonomy of the three interrelated registers with a discussion of disability as a narrative resource. Through the work of Leslie Fiedler and Arthur Frank, she suggests the potentiality of disability in the generation of vivid narratives, created for both the disabled and nondisabled. Fiedler (as cited by Garland-Thomson, 2012) documents his conception of disability as one that serves as a narrative resource for the world of the ordinary, using disability to confront the world of the familiar and comfortable. To Fiedler, the extravagant manifestation of disability provides world-changing encounters to the "ordinary," encounters that contribute to the cultural work of teaching the nondisabled how to be more human. Fiedler cites Mary Shelley's monster in *Frankenstein*, William Shakespeare's character of Caliban in *The Tempest* and many other significant cultural figures in his analysis of how "true freaks"²¹ inspire wonder. Without being too enigmatic, according to Fiedler, it is the encounter with disability that teaches one to be more human; in and following the encounter, one starts to realize that the differences are less drastic than they appear at first glance. In this sense, the wonder is the narrative resource.

Arthur Frank (1995) also values the narrative potential of disability, not for the nondisabled but rather for disabled people themselves. He argues that sooner or later, all will become incapacitated, so in a sense, disability is a resource for us all. When one is able to seek out a disability story—or even author their own "self story"—experience is transformed into a "survival kit" for others (Frank, 1995). Following the arbitrary temporal incident(s) that may

²¹ Fiedler terms "true freaks" as those who "challenge the conventional boundaries" (1978, p. 344).

precipitate the acquisition and experiential transformation into disabled embodiment, Frank suggests using disability as an opportunity to develop “voice”. Through voice and its work in the creation of a narrative, one is able to put order to the chaos of experience. One is able to offer that to the world in ways that allow bodies to join in their shared vulnerability; in this sense, Frank (1995) articulates a conservation of disability as an antidote to disqualification, challenging the dividing line between disabled and non-disabled.

4.1.2 Disability as epistemic resource

Garland-Thomson (2012) begins the next section by revisiting the generative work of narrative as a mechanism of knowledge production through the rendering of life experience into a structured form. When unique knowledge is produced through narrative, such information can be considered an epistemic resource. Take for instance a person with a disability, whose “embodied cognition” graces them with an exclusive perspective, distinct from those whose bodies conform smoothly to the traditional environment. Garland-Thomson (2012) utilizes “embodied cognition” in referring to how “our bodily form, function, comportment, perceptual apprehension and way of mind shape how we understand our world” (p. 345). Garland-Thomson (2012) uses deaf and blind activist Helen Keller as an example here to illustrate the generative opportunity in developing one’s ability to smell, taste and touch—senses and abilities that often remain inactive in one who is able to see and hear. When one is unable to interact with a world not built to accommodate them, to adapt, they must develop subjugated knowledge. This register deems subjugated knowledge, developed through learning to live effectively in an environment built for someone else’s body, as something that is generative.

Garland-Thomson (2012) also mentions musical theorist Joseph N. Straus in this context, as his work with music and “disablist hearing” formulates a vocabulary of generativity over deficit. According to Straus (2011) when one is hearing impaired, it is not that they are unable to experience music; instead, Straus claims that particular kinds of embodiment might have an effect on musical hearing in unique, useful and fascinating ways. As this occurs, disablist listeners, as Straus (2011) asserts, “may hear things in music that normal listeners do not” (p. 347). Straus argues that these non-traditional methods of the musical encounter may expand our understandings of musical experience and production. In another work, Straus (2013) conceives people with autism “as a social group with a distinctive, shared culture” (p. 462). Throughout, he

argues that individuals claim autism as a valued identity, both socially and politically, and celebrate it as a shared culture of art and everyday life. The prevalent qualities supposedly inherent to the diagnostic criteria of autism (reflective of the medical model of disability) such as weak central coherence, deficits in one's ability to socially relate to others and deficiencies in executive functioning, can actually be seen as helpful, Straus (2013) claims. It is precisely through the culture that is produced by autistic people—including writing, art and music—that autism becomes a distinctive and valued identity.

Bauman and Murray (2010) also explore how deaf ways of being in the world are culturally contributive, in that they may offer vital contributions to human diversity. The authors ask: how does being deaf reorganize what it means to be human? In response they state that embracing deaf people and their alternative dialects will habitually lead toward a greater understanding of the human penchant for adaptation; in this sense, similar to Keller and Straus, disability, and the lessons inherent to it, are revaluated and reconceptualized as something of value.

4.1.3 Disability as ethical resource

When disability generates narrative, narrative produces knowledge. When this type of distinctive knowledge is generated, Garland-Thomson (2012) argues that it is ethically counter-eugenic. She uses Michael J. Sandel and his work on ethics and genetic engineering to illustrate such a contention. Sandel notes that children are to be appreciated as they come—they should not be considered as objects of design; in this sense, Sandel advocates for children, particularly children born with disabilities, to be accepted rather than eliminated and controlled through efforts such as genetic engineering. In our modern society, Sandel (2007) presents this as both an ethical choice and opportunity, despite our hauteur to control the shape of the future (inherently eugenic). An interesting facet of Sandel's argument is his notion of embracing the unexpected in order to not lose our humanness. When individual's attempt to master the universe, there is a risk of destroying things inherent in humanity—our giftedness, our achievements and, especially, our uniqueness. Rather than live in a molded and managed world, Sandel asks to live in a world that abides the unexpected; disability in this capacity functions as an ethical resource.

In Sandel's (2007) article "The Case Against Perfection", he cites theologian William F. May's "openness to the unbidden" (p.56). Garland-Thomson (2012) interprets this idea as a permit to cultivate unanticipated resourcefulness or opportunities for flourishing. She argues that

disability could present this to the entire human community. In her words: “Disability in general offers an experience-based counter narrative to the modern subject’s understanding of the present moment as an opportunity to shape the future” (p. 351). That is to say, when one is unable to entrench themselves in a predictable life trajectory, they are rooted in the present. This idea is precisely what this study attempts to disclose: how disability can be a resource for rethinking temporality. Perhaps one of the gifts of disability—a counter eugenic argument in itself—is that it illuminates the plurality of time, as opposed to the singularity imposed by the dominant form of linear temporality as discussed above. Both Sandel (2007) and Garland-Thomson (2012) allude to this idea, and it is precisely what will be examined in the research undertaken for this thesis.

Thus, guided by Rosemarie Garland-Thomson’s (2012) bioethical assertion that the world might want to conserve rather than eliminate disability, I will conclude with the proposition that those who possess an alternative relationship to time disclose opportunity with regards to responding to the question regarding our shared precarity. I will suggest that there is something to be learned from these individuals, from those who have been excluded epistemologically from society due to marginalization from the choreography of everyday life (Paterson, 2020). In short, perhaps there is a resourcefulness inherent in their perspectives. Answering this question, and those that emerge through my research, will provide new discernments and expand upon existing insights into the case for conserving disability. Going beyond Garland-Thomson (2012), I will also explore the broader implications of alternative temporalities, both for how one is to position themselves in the world and how they can engage with others. In short, I desire to disclose both the plurality and generativity of alternative conceptions of time.

Chapter 3: Research Design and Methods

In this chapter, I describe the qualitative design that I used to achieve my research purpose and address my research questions described in Chapter 1. Drawing on the non-eugenic framework of approaching disability described in Chapter 2, my objectives were to examine:

- How parents of children with complex physical and intellectual disabilities grapple with having no “systematic” trajectories for development.
- Alternative temporal logics and lessons deriving from insights of parents’ own accounts of grappling with normative temporality.
- The potential implications of alternative temporalities and the possibility of them affecting how we position ourselves in the world and how we engage others.

My approach to research design was twofold: I first had to develop a particular disposition in order to relate, be challenged and deeply engage with the material of study. I then had to use qualitative methodology as a tool for organization and analysis.

Because this research project was strategically designed to garner and interpret information from four memoirs, I recognized the necessity of an open constitution. In light of my own prior learning, I felt that a philosophical hermeneutics approach would be appropriate to employ in this context. Attesting to Hans-Georg Gadamer’s reflections on art as primarily an experience of meaning, Nielsen (2016) discusses the importance of approaching “artwork as an other disclosing a message with the potential to facilitate new ways of seeing” (p. 7). She continues by saying that when art is seen solely as a means of consumption or pleasure, one misses out on the potential of a transformative encounter. Thus, this work did not desire to perceive each memoir as a constructed, subjective aesthetic; rather, through the deployment of a hermeneutic disposition of openness, I approached each as a source of cognitive truth and value with the potential to change, disrupt and transform the reader. According to Nielsen’s (2016) interpretation of Gadamer’s notion of aesthetic non-differentiation, when one enters into the world of the art—or in this case, the text—one must be open to the troubling and unsettling of one’s previous perceptions of the world, self and others. As Nielsen puts it, “Art does not take us out of this world but enables us to see the world with new eyes” (p.7). In this sense, the memoir serves as a rich articulation of a subject matter, possessing truth and opportunity should the

reader be active, open and engage deeply (referred to by Gadamer as the “expanding of horizons”).

In addition to the employment of hermeneutics as a disposition to allow the truth of an other to expand my horizon, I had to utilize a practical modality in order to ensure a sufficient degree of analysis was undertaken with the content. Thus, general facets of qualitative methodology were loosely retained to help keep data extracts, codes and themes organized, coherent and reliable. This will be discussed in a subsequent theme of this chapter.

In sum, to explore how parents grapple with the experience of parenting according to an alternative temporal narrative, this work turns to the unsolicited voices of a mother and three fathers, as expressed in their book-length personal memoirs. As memoirs are written over time, and in some ways about time, they can challenge and inspire while connecting readers via real-life experiences (Lynch, 2019); in other words, from a philosophical hermeneutical perspective, memoirs serve as the ideal “other”. It is important to regard Couser and Mintz’s (2019) testament that memoirs demand a shaping of memories into something that has meaning for others. In this sense, memoirs can be perceived as aesthetic sources with temporal underpinnings. They were constructed at a particular time and at a particular place. However, in line with Gadamer, Nielsen (2016) notes that “artworks are not silent objects confined to their own time and place; rather, they call out to us and await a response” (p. 11). If their disclosure disrupts our previous way of seeing the world—in line with a philosophical hermeneutic disposition to engagement—then perhaps they retain a position as a truthful articulation of the subject matter in the present and perhaps even the future. Thus, this project sees memoirs both as a constructed vessel for the past as well as a source of truth in the present.

1. Memoirs as Qualitative Data

According to Power and colleagues (2012), there exists a reservoir of knowledge within the published autobiographies of people who have recorded their experience in writing. In their paper on “Autobiography as genre for qualitative data,” the authors propose literary published autobiographical accounts as “an inexpensive and readily available source of narrative” (p. 40). Although they argue for the benefits of autobiographies, memoirs—also written by authors who desire to express their life experience to others—are just as, if not more, useful for the uncovering of significant experiences; the only difference between the two is the timeline

covered in the writing. According to Lynch (2019), autobiography concentrates on the chronology of the writer's complete life while a memoir encompasses a significant or defining period of time. In this sense, due to the sheer difference of volume in articulating the experience, a memoir may contain a more holistic rendering, offering emotion, sensory experience and reverie, in addition to an experiential account. Nonetheless, writing either an autobiography or memoir allows the author to remark upon an experience from their own perspective, in their own words, focusing upon the aspects of the experience that were most meaningful to them (Power et al., 2012).

In the context of qualitative research, published literary memoirs are relatively accessible and are easily sought out. Little effort is required to collect a sample—autobiographies and memoirs are typically publicly available (Power et al., 2012). As data, both autobiographies and memoirs can generate new understandings about an experience. According to van Manen (1997), an analysis of the type renders “a rich ore of lived-descriptions” (p. 72). Because the author of the experience is the expert in articulating and establishing the narrative, it can be perceived as free from professional assumptions²². Although the role of memory and “truth” in offering the narrative is something that is contested (i.e., retrospective reflection may result in the author engaging in conscious and unconscious manipulation of the memory), Stanley (1992) notes that a representation of an objective “truth” is something that no qualitative data can ever truly claim. Similarly for Gadamer, while there is a truth in art, it is not timeless truth, but a rendering of the world that makes sense, always open to revision in light of ongoing experience. If a certain rendering of experience is shared through a memoir, and that experience sheds light on the world—helping us to understand ourselves and the world differently and in a broader aspect—from a hermeneutical perspective, there is truth.

Power and colleagues (2012) comment on the rare use of autobiographies and memoirs as data sources. This is perhaps due to questions of validity raised by traditional empiricist research cultures. Lareau (2012) argues the social sciences appear to be under siege, as terms such as “variable” and “hypothesis” creep into the qualitative realm as ideal components of quality methodology. In this sense, researchers are being trapped into a relatively narrow conception of

²² Because the memoir is closed, unlike conversations that are amenable to elaboration, Power and colleagues (2012) note that the reading and interpretation of material will differ between readers depending upon their beliefs and experiences. As mentioned, this work takes a philosophical hermeneutical approach to analysis.

scientific research. Yet, on the basis of an other's ability to shed light on a particular subject matter, memoirs perhaps serve as the ideal participant in a lot of ways. The descriptions are long and detailed; they cover long periods of time; and they are constructed thoughtfully, thoroughly and effortfully. From the context of research and its mission to investigate phenomenon, this study leverages the utilization of memoirs as a valued source of cognitive value and truth.

2. Memoir Selection

Data selection was based on broad criteria and required only that the memoirs be available in English, written from a first-person perspective by a parent of a child with some sort of disabled embodiment and available for purchase via a publishing house. The first two memoirs chosen for inclusion were revealed in Garland-Thomson's (2012) "The case for conserving disability," where she spoke about Emily Rapp's experience parenting a child with a fatal disease as well as Chris Gabbard's account of parenting his son living with a set of significant disability traits. Both of these individuals, whom Garland-Thomson references, were authors of memoirs that satisfied the broad inclusion criteria, and thus, were included in the study to get a fuller appreciation of the value of these memoirs. I had been familiar with George Estreich's work on the flaws inherent in genetic engineering from a previous time, so after some exploration, I had found he had also written a memoir about his experience raising his daughter with Down syndrome. This memoir was also included in the study. The last memoir, *The boy in the moon*, was uncovered via the means of a simple search on the search engine Google. The following search term: parenting memoirs, brought up an opinion website with the *50 best memoirs from the last 25 years*. Ian Brown's memoir was listed at number seven. His book also satisfied inclusion criteria as he is a parent of a profoundly disabled son. In conclusion, all were sought out of convenience, but all satisfied the criterion established and, of course, all had much to say about alternative temporalities and grappling with linearity (see Table 1 for further details).

In what follows, I will be offering a succinct synopsis of each of the four memoirs with the intent to brief the reader to the context of the given parent and child relationship. Each relationship is defined as a parent writing about their child, the central character of each of their works.

TABLE 1. Overview of the analyzed memoirs (in chronological order)

Author	Book title	Year of publication	Publisher	Number of pages	Child and diagnosis	Synopsis
Emily Rapp	<i>The Still Point of the Turning World: A Memoir</i>	2013	Penguin Books	264	Ronan; Tay Sachs disease	Throughout the narrative, Rapp grapples with the fact that the future has been taken from herself and her son.
Ian Brown	<i>The Boy in the Moon: A Father's Journey to Understand His Extraordinary Son</i>	2009	Vintage Books	293	Walker; Cardiofaciocutaneous syndrome	A father's attempt to find a cure for his son's cardiofaciocutaneous syndrome leads him to learning to accept his boy just as he is.
Chris Gabbard	<i>A Life Beyond Reason: A Father's Memoir</i>	2019	Beacon Press	226	August; "serious neurological dysfunction" causing developmental/physical/visual gaps.	The author experiences a philosophical transformation in the ways in which he conceptualizes humanity and science following the birth of his son with a severe traumatic brain injury.
George Estreich	<i>The Shape of the Eye: A Memoir</i>	2013	Penguin Group	314	Laura; Down syndrome	Tells the story of his family as his daughter is diagnosed with Down Syndrome.

2.1 *The Still Point of the Turning World: A Memoir*

Published by Penguin Books in 2013, *The Still Point of the Turning World* is a memoir written by Emily Rapp. She offered the narrative as the story of her son, Ronan, who, at nine months, was diagnosed with Tay Sachs disease. Tay Sachs disease is a fatal and terminal disorder that results in progressive destruction of the nervous system (Ramani & Sankaran, 2022). Rapp describes her research into the disorder: “Nerve damage begins in the womb and progresses quickly, leading to dementia, decreased interaction with the environment, seizures, spasticity, and eventually death” (p.4). Ronan Rapp, born in March of 2010, is diagnosed with this grave disorder during his infancy and his parents are told that there is no cure. Rapp perceives the diagnosis as a “death sentence” (p.4) and wrestles with the idea that her son is going to die. Throughout the story, Rapp prepares to lose Ronan and, in doing so, revises all the things she perceived parenting to be. She grieves for her son, experiences profound bliss and dread for both his and her life and reckons with the search for a new sense of meaning. The narrative offers a powerful account of a woman’s love for a dying boy. It concludes with Ronan’s death just after his third birthday, on February 15, 2013, leaving Rapp lamenting, grieving and vulnerable, but also filled with unconditional love, gratitude and presence.

2.2 *The Boy in the Moon: A Father’s Search for His Disabled Son*

Originating as a *Globe and Mail* series, Ian Brown writes *The Boy in the Moon* searching for the inner life of his son, Walker, born June 23, 1996. Published in 2009, the novel begins with the disclosure of a typical night at the Brown household, where Brown attempts to lure Walker to sleep through means of medication and physical restraints. This is due to Walker’s diagnosis of cardiofaciocutaneous syndrome, which factors into his motivation to self-mutilate. Other characteristics Walker possesses, as symptomatic of this rare genetic disorder, include a mild heart murmur, difficulty in chewing and swallowing, an inability to verbally speak, compromised vision and hearing, as well as poor muscle strength. “Symptoms ranged wildly in severity and kind [...] physically, he’s better off than many CFC children [...]; cognitively, less so” (Brown, 2009, p.8-9). Throughout the memoir, Brown questions the value of his son’s life, and in doing so, grapples with the notion of disability and how society both understands and misunderstands it. As the narrative progresses Brown learns how “a disabled child teaches you to make your own

rules” (p.101) as well as how Walker could be “a lens through which to see the world more sharply” (p. 243).

2.3 *A Life Beyond Reason: A Disabled Boy and His Father’s Enlightenment*

In 2019, Chris Gabbard, a professor of English at the University of North Florida, published a memoir entitled, *A Life Beyond Reason: A Disabled Boy and His Father’s Enlightenment* through Beacon Press. This story details the philosophical transformation Gabbard experienced following the birth of his son with a severe traumatic brain injury. August David Gabbard, born on March 5, 1999, experienced a lack of blood and oxygen “before or after the birth, which caused brain damage” (p.28). Despite Gabbard’s reliance on science, medicine and the Enlightenment as attestation of humankind’s ability to control its destiny, Gabbard claims that the medical industrial complex failed August, Ilene (August’s mother), as well as Gabbard himself. Although this mistrust gathered from the malpractice would prompt a shift in priority for many, it was August who for Gabbard prompted the movement from an emphasis on “the examined life” to the importance of a “life filled with love”. By the end of the story, as the title of the memoir suggests, Gabbard no longer equates human value with intellect and potential, but rather, “the ability to love and relate to others, perception, [and] delight in movement and play” (p.121). This perception assisted him particularly as August began to “arch” and experience immense discomfort as a result of a pump implant; unfortunately, August passed on October 14, 2013. Gabbard concludes by saying, “I can no longer call myself an atheist” (p.221); it was August who prompted him to re-examine his deepest assumptions about the value and purpose of a human life.

2.4 *The Shape of the Eye: A Memoir*

“I felt that Laura’s life was valuable... I also felt that our lives were over” (p. xv-xvi), writes George Estreich, author of *The Shape of the Eye*, published in 2013 by the Penguin Group. This quote predisposes the audience to the theme of Estreich’s memoir, that there are two kinds of stories told about disabled children, a “hopeful” one and a tragic one. In February of 2011, Estreich’s daughter Laura was born with no complications—it was just that her eyes appeared slightly almond shaped. After some tests, it was confirmed that Laura was born with an extra twenty-first chromosome, also known as Down syndrome. Estreich is dumbfounded at first, resistant to the unfamiliar and non-normal world in which he now resides—a world that fell

outside of the narrative that he was familiar with, without a clear narrative to hang his experiences onto. He had already formed a future in his head prior to the birth and diagnosis based on his experience with his first daughter. And so, Estreich embarks on his journey to acceptance and—similar to Rapp, Brown and Gabbard—uses his own writing and literary talents to fill in the absence of the unfamiliar. He concludes by asking his reader to cease to deny the “sense of possibility that we ourselves take for granted” (p.288). All those lists about the characteristics of Down syndrome that were given to Estreich when he was in the foreign land of the unfamiliar had no room for a story; he concludes that each individual should be given the right to mystery.

3. Data Analysis

According to Miles and Huberman (2014), data collection and analysis are intertwined with each other in qualitative research. Data for analysis included solely the narratives shared through each of the four memoirs. Each was analyzed for key themes, which, according to Green and Thorogood (2009), is the most common approach to qualitative data. The study involved categorizing the recurrent or common themes in the content of the data based on a deductive approach. Rather than seeking to gather a rich description of the data overall—similar to the narrative analytical approach (see Riessman, 2008)—this work pursued a detailed analysis of some aspects of the data. Theme development was based how time figures into the accounts of each of the four relationships in study. Earlier in the chapter, a distinction was made between the disposition necessary to make sense of the memoirs and the methodology employed to ensure a sufficient degree of exhaustion was undertaken with the memoirs. In order to organize my philosophical hermeneutical orientation to the material, I used qualitative methodology as the practical modality in an effort to ensure that I went through all the material well. This followed the tarrying, the living, the engagement, and, from a hermeneutical standpoint, the dialogue with these works. My research was strategically designed to possess both an open disposition as well as a methodological component, which had me be more analytical and technical.

In the employment of this philosophical hermeneutical disposition, data collection and analysis were perceived as a dialogical encounter, where the researcher sought to understand within the interplay of the perspectives present in the encounter, constituted in historical consciousness and cultural contexts of each participant (i.e., the reader and the other [the author])

(Gill, 2015). In this sense, each of the four memoirs were to be perceived within the context of the researcher's own "boundness" in order to condition an understanding that allows a new "horizon" to form. If understanding is achieved, this newly formed horizon, referred to as "our range of vision, which includes everything that can be seen from a particular vantage point" (Gill, 2015, p.14), can help to overcome the limitations of the previous scope. Put another way, the analysis required an openness to the memoirs in order to acquire meaningful understanding of what the author was truly saying for lessons to be learned. In what follows, I discuss the other component: the methodological component and the specific data analysis procedures I used to provide rich descriptions about alternative temporalities and alternative ways of being in the world as reflected in the parents' accounts.

The data analysis involved two main procedures: reading and memoing; and describing, categorizing and interpreting. Analysis was based loosely on Virginia Braun and Victoria Clarke's (2006) application and evaluation of thematic analysis. This is a constructionist paradigm due to its flexibility in acquiring rich, detailed and complex accounts of data (Braun & Clarke, 2006). Again, of course, philosophical hermeneutics guided this process, but Braun and Clarke (2006) brought structure through the offering of a step-by-step guide in performing qualitative thematic analysis. The process was iterative and required a constant moving back and forward between the data set and emergent themes.

As mentioned, the first step in the analysis process involved reading and writing memos on the memoirs. The aim of this step was to get a general sense of the data as whole. Texts were read repeatedly and intensively to allow for an immersion in the details (Schmidt, 2004). Initial ideas were disclosed right from the first interaction with each of the texts; this was prior to the generation of initial codes. Sticky notes were used and attached physically to relevant sections of data that were to be visited later. As well, memos—which included page references and identifiable sections of text—were written in a notebook to document ideas or concepts that struck me as important for answering the overall research question and aims. As stated, each of the memoirs was read several times in order to allow for an acquaintance to be established with the different aspects of the data; this close reading is reflective of the ideals of philosophical hermeneutics. By the end of the third reading of each text, an initial list of potential codes was established. As well, data extracts (i.e., excerpts of text) from each memoir were transcribed onto

Microsoft Word for later analysis; the data was extracted verbatim and was then checked against the books for accuracy. The transcription process allowed for a fourth close reading of each text.

The next step in data analysis involved describing, cataloguing and interpreting the data extracts. As mentioned, by the end of the third reading, an initial list of ideas was produced; from here, Braun and Clarke (2006) recommended organizing the data into meaningful groups. Since I employed a deductive approach to analysis, the data was coded around the specific research questions in mind. NVIVO software was used to perform coding. First, each individual memoir transcription which included a multitude of extracts from the work was loaded onto the software and a long list of codes was generated using the “nodes” function on NVIVO. Next, each transcription was read over again, with the researcher highlighting and sorting the various data extracts into the pre-established, thorough, inclusive and comprehensive codes. Each data item was given equal attention in the coding process and all relevant extracts for each concept were collated (Charmaz, 2006). Following such cataloguing, the codes and collations were sorted into potential themes; this was done via a close and careful consideration of the relationships between the codes and the overall distinctions between them. Themes were then reviewed; as stated by Braun and Clarke (2006), this was a two-step process involving the assurance of theme coherence as well as the assurance of identifiable distinctions between them. Each theme was defined and refined by going back to the collated data extracts and organizing them into a coherent and internally consistent account; a narrative was written to accompany each specific theme (Braun & Clarke, 2006). To conclude, themes were checked against each other and back to the original dataset (Charmaz, 2006), and—reflective of philosophical hermeneutics—parts were revised in light of the ever emerging whole.

4. Ethical Considerations

Publishers were not contacted regarding this paper. Though all data were amassed from public sources via accredited publishing houses, issues of privacy, anonymity and consent must still be considered (Zimmer, 2010). Because it would not be possible to shed identifiers from each source of data, this research does not accord with anonymity nor confidentiality. To add, although each of the four authors wrote their accounts for public consumption and all explicitly expressed desire to promote improved understanding of parenting a child with a disability, this work appreciates that that is not the same as submitting their chronicles up to

be analyzed, likened to other narratives and then offered out of the initial context (Welch, Polatajko, Rigby & Fitch, 2019). In view of this, I makes every effort to be respectful of the data.

Chapter 4: Findings

In this chapter, I examine how four parents invoke time and temporality in the raising and development of their disabled child, as well as the insights they have gained and share within their narratives. In line with critical disability theorists, I was principally interested in the cultural contributions that their atypical temporal experiences may offer as a result of their unconventional experience in raising a child with a disability.

Through thematic analysis, four themes were developed that highlight the experiences and insights described by Rapp, Brown, Gabbard and Estreich. In addition, I included a final meta-theme that was meant to connect the four themes together, within the context of temporality. The first theme, *Confronting the “precedent,”* relates to experiences of grappling with temporal normality and typical parenting trajectories, following the diagnosis of their child and the proceeding exclusion from (or mitigation to re-enter) the linear temporal framework. It also highlights other feelings of living in dread of the future, confronting one’s preformed idea in their head, reacting to the standard model and giving up the potential child. The second theme, *Acceptance of child,* encompasses passages in which Rapp, Brown, Gabbard and Estreich share their insights regarding how they come to accept and see the value in the life of their child, as opposed to the unease which they may have experienced at the onset of diagnosis or unconventional entrance to the world. It relates heavily to the role of the parents themselves, demonstrating how each of them come to enjoy the child as they are, as well as seek and ponder the inner life of their small being. The third theme, *Imagining a life together,* includes Rapp, Brown, Gabbard and Estreich’s descriptions of how having a child with a disability allows a parent to, alongside their kin, invent their own world to live in together. It features the transition from grappling with the precedent to an alternative space of parenting and “being”, where some of the significance is stripped away from what society deems as important. Concepts such as in-the-moment parenting, telling stories as a method of coping, and imagining how the world could be, are included to illuminate how these parents come to value the use of imagination in their lives. Lastly, *Reclaiming the mystery,* relates to the giving up of the need, search and requirement of control. It incorporates passages in which Rapp, Brown, Gabbard and Estreich share their insights regarding how there are many ways of being human, and how there is value and insight in all of these alternative ways. The theme heavily relies on each of the author’s assurances that

comparison is futile and therefore perhaps we should abandon our systemic grip on reason, progress and mastery as the only narrative of “becoming”, even if just by a little. It highlights how a “list” has no room for a story, and how society should move away from its emphasis on the “single story”. All four of these themes are encompassed by one meta-theme: *Temporal insights gained through disability*, which I offer as the overarching idea that Rapp, Brown, Gabbard and Estreich describe, which is that something lies beyond the linear temporal framework and that there is potential in this alterity.

1. Confronting the “Precedent”

In the offering of their experiences, Rapp, Brown, Gabbard and Estreich frequently talk about how they have each had to grapple with the “standard” regarding parenting, typical developmental trajectories for their children and normality. Their accounts often pair contradictions between heartbreak and grief at their exclusion from the norm, alongside the bliss and happiness they experience in the day-to-day experiences of raising their child. They discuss their confrontation with linear temporality and the ideologies implicit in it, including developmental milestones, published parenting guides and advice, and the widely known “potential” of children. They also discuss their dread for the future when they inevitably compare their children’s trajectory to the normative child’s trajectory.

1.1 Grappling with normality. The four parents describe the difficulties implicit in their inevitable opposition to the temporal norm. They assert that typical parenting advice is often marked by future-oriented thinking; how to optimize a child’s sensory, language and physical experience, how to prevent colic and other illnesses, and how to equip children with the skills to be social in the future, among other things. Ultimately, each ends up wrestling and grappling with normative frameworks of development and most accessible parenting guides for the “typically developing” child, which are so deeply entrenched in our lives. As Rapp states:

I realized that it was very likely that had it not been for Ronan’s terminal diagnosis, I’d still be living out these old stories through my unsuspecting son. It took this experience to help me see clearly, to understand that the bulk of popular parenting advice champions an approach to living that completely compiles with achieving bogus standards of success, but that didn’t mean I was immune to longing for those meaningless benchmarks. (p.18)

The memoirs also discuss how society appears to be organized around this idea of temporal transformation in Western culture, where progress and achievement mark betterment for tomorrow, and where “going backwards” is synonymous with failure. It is normal for a child to start at point A and gradually develop towards point B—not to stay at point A longer than what is typical for others. Rapp’s son, Ronan, for instance, diagnosed with Tay Sachs disease, will never be able to drive toward a future resolution; he has a “death sentence,” in Rapp’s words (p.5). Rapp wonders what his life means in a world where it is the standard to develop according to a pre-defined guide and milestones to attain an endpoint of success. Gabbard ponders the same in his reflection on how others see August, his child:

[August went to the day care at the Child Care Centre at Presidio Heights]. Over time we noticed that some of the parents of the other children [at Presidio Heights] were not comfortable with August being there. He was toddler age, but already he was perceived as different—as bearing stigma—because he couldn’t toddle. These parents didn’t want their children to be exposed to someone like him. ... These parents wanted to shield their children from ‘life’s harsh realities’—meaning our son—assuming that he would frighten their kids. But the only harsh reality was the fact that he frightened the adults, not the kids. [...] The children, though, weren’t put off at all by August. (p.43-44)

The above quote illustrates how these parents grapple with normality implicit in a linear temporal framework and its pervasiveness as an ideology; adults mark August as different and feel the need to protect their child from such a unique experience. Temporal normativity makes people desire a standard experience for themselves and for their young child—the standard is the catalyst for expectation and future-oriented planning. When one transgresses the standard, such as August as described by Gabbard above, adults are stunned and illuminated to *what could be*. This *what could be* is what is non-normative and therefore, undesired. It goes without saying that this value rendering is at the expense of someone else’s experience and results with parents unable to abide by typically developing, or normative standards.

1.2 Excluded from normative timelines. As a result of each of the parents’ experiences in grappling with normality, it appears that they quickly learn that they are to be excluded from the linear temporal framework. Once again using Rapp’s son, Ronan, as an example, it is clear how he is unable to live linearly: Rapp cannot give to him the experiences of music class and swimming lessons simply for the purposes of manifesting some fabulous talent; all she can do is create experiences for him that would make him happy in the moment. As she states:

As I sat down to write, I bristled at the lack of information and resources for parents who are not concerned with whether or not their children will be admitted to Harvard or win prizes for piano performances or even be productive and gracious or successful in school, but are instead involved in the daily grind of making the short lives of their children as full as possible for two, three, maybe six years at the outward reach, depending on how the disease progresses and the levels of medical intervention. (p.11-12)

Rapp and Ronan are excluded from the linear temporal framework due to the promise of no future for Ronan. This contrasts with the experiences of Brown and Walker, Gabbard and August and George and Laura, who, instead, are encouraged to employ mitigation strategies to re-assert themselves back on the typical and normative temporal framework. All three fathers report, following the diagnosis of abnormality in their child, doctors and other medical professionals telling them to anticipate improvement if the appropriate therapies are put in place. Again, this reflects an emphasis on the future and, hence, is a representation of linear temporality. On this point, Gabbard writes:

But before she had a chance to continue her line of questioning, all four doctors began redirecting us toward a focusing on the future. Now came a barrage of happy talk. There was a legitimate basis for it: recent research was showing the neuroplasticity of the brain and its capacity for adaptation to change, including structural reorganization following injury. This was a newer model, the older one having assumed that brain cells die due to injury and then permanent loss of function follows. The new model gave grounds for anticipating improvement. (p.33)

This work recognizes the wondrous benefits of neuroplasticity and the brain's ability to adapt following some sort of disruption; however, the onus is on the family to seek out this neural reorganization through early physical, cognitive and occupational therapies and mitigate damage in order for the ideologically valued relationship with the future to flourish. This optimism for intervention to eventually achieve typical milestones reflects once again what is temporally standard and also showcases how alternative relationships with time, such as Ronan's, are undervalued. Put differently, the importance lies in children eventually achieving developmental and normative milestones. As Brown states:

There's an entire room on the third floor, next to his bedroom, dedicated to the storage of toys he's never played with and clothes he's never worn—the archaeological history of our futile belief that this or that plaything would pull him out of his closed-off world, into our own public space. They rarely did. (p.18)

1.3 Shifting trajectories. Rapp, Brown, Gabbard and Estreich all discuss their eventual shift to an alternative temporality following the diagnosis and process of coming to know their child.

This was the result of their resistance to temporal normality, as discussed above. As mentioned, parents were not able to consult normative frameworks and parental guides and textbooks—they described what the “typical” child was to achieve and at what moment. Thus, each asserted that there were little to no stories accessible that aided them in the development of a “comfortable” structure that they could follow. As Estreich writes:

We had not only lost our own story, but the possibility of *any* story. A story, in its very structure, offers comfort. Even the bleakest story has a curve or action—a beginning, middle and end—and so it offers the possibility that experience can have an intelligible shape. But having a child with Down syndrome did not map onto a rising or falling curve of action; the event derided every curve. It spoke of chance, not continuity—in the original meiotic error, by which the extra chromosome came to occupy an egg or sperm, and now, in the array of dire probabilities the pamphlets disclosed. So we felt clueless, benighted, deceived. For months it had been true. We had not even known what our story was. (p.16)

And so, parents are given the responsibility to create their own narratives and trajectories which they would follow in the raising of their children. As for Rapp, she had to incorporate the worrying reality that her child would not be launched into a bright and promising future, but rather one that included his grave. Thus, her temporal trajectory was grounded in the everyday, raising and providing Ronan with “dignity and minimal discomfort” (p.12) as opposed to future-building learning experiences. On similar lines, Brown, Gabbard and Estreich described their grappling with the temporal precedent to an alternative space by opposing the modern task of parenting where one is to ensure that their child is prepared from the onset with the tools that will lead to acceptance in the best educational pursuits, which will in turn lead to the most successful adult life. For Estreich, this transpired with an acceptance of an alternative timeframe which Laura would develop in relation to her older sister Ellie:

The real difference, this time around, was our consciousness of the process. We were aware, as we never had been with Ellie, of stages within stages, markers, milestones. With Ellie, it was simple. Each day she stood a little longer, and there she was: stable, walking. We felt like lucky witnesses, not therapists. With Laura, we counted the seconds. Laura’s development was more likely to be divided into named steps, and the steps were more likely to be quantified. Because Laura received services specified in her Individual Family Service Plan, these steps were further classified into gross motor, fine motor, and adaptive categories, and assigned as six-month or one-year goals. [...] With Ellie, we learned to speak the language of childhood; with Laura, we became linguists, studying its formal grammar. (p.140-141)

1.4 Dread for the future. Such a move to an alternative trajectory for parenting transpired into mutual feelings of dread for each of the memoirists—dread for the future, even amid some acceptance of their child’s atypical developmental experience. For Rapp, this dread of the future was obvious as a diagnosis of Tay Sachs disease inevitably results in premature and early death. Thus, she and Ronan lived together in the presence of the temporal moment, and she remarked that it was very often “profoundly blissful” (p.25), while acknowledging that it did not detract the feelings of terror creeping into their encounters. As she describes:

On Memorial Day, I thought about the kids and babies with Tay-Sachs who had died, those who would die in the next year, and especially the new babies who would be diagnosed and what those parents would experience, that terrible premourning for an inevitable death. The burden of knowing what will happen (although not necessarily in what order) and knowing you will be there to witness it: a kind of death experience, no doubt. Every day was an alive day with Ronan, and built into that celebration was the dark shade of a future Mourning Day. The constant push-pull: here but not for long. What will come next? Why is this happening to my child? Why is this happening to me? (p.202)

Rapp was not alone in such an experience. Brown described his dread at the future with Walker as one that would involve series upon series of challenges to be overcome, with no end in sight and no glory to be sought. He discussed his trepidation for both the immediate challenges and the long-term challenges, particularly in regard to what would happen to Walker once both he and his wife, Johanna, died. This far-reaching anxiety appears to be a common fear for each author, as Gabbard described the same. Yet Gabbard commented on how the anxiety results less in future-oriented thinking, but rather in alternative temporalities. He remarks:

Families with children who are healthy and typically developing experience a privilege of which they are not aware. Those families with children who are disabled or suffer from serious health problems constantly live in dread, always waiting for the other shoe to drop. Parents can barely think beyond the here and now when they know that they are only one phone call away from a crisis that will engulf them. (p.83)

Estreich described his feelings similarly, especially when it came to Laura preparing to have cardiac surgery to remedy her congenital heart defect. He stated, “Now we tiptoed in fear of an avalanche. Laura’s surgery would happen in a month, if all went well, if she gained weight, if she didn’t get sick. If. Behind the days, an endless murmur of worry” (p.57). Consequently, this dread, fear, anxiety and worry about the future was rooted in the present, in each of their alternative relationships to time. Rather than looking forward to what was to come and the

future—as the precedent recommends—they often wondered “what’s next” (Rapp, p.133) with trepidation and unease, seeking to extract themselves from such a linear orientation. With reference to dreading the future, an alternative temporality is referenced here, one that consists of parents barely thinking beyond the here and now but, at the same time, having no consolation from the future.

1.5 Letting go of potential. To foreshadow discussions to come, each parent eventually ended up accepting each of their children for who they were and the value they elicited in the world. However, this required a *letting go* of the potential child, the one they had preformed in their head prior to conception, during the gestation period and just before diagnosis. This may have not been easy for each of them, but it had to be done. Estreich contextualizes this idea in his memoir by offering his perspective prior to the arrival of his second child (Laura), about what he wanted that child to be: “happy”, he states (p.9), but notes that this assumption was rooted in the ignorance that this child would be born with forty-six chromosomes as opposed to forty-seven, inherent in Down syndrome. Rapp agrees with him regarding this naivete, asserting that that it was Ronan’s terminal diagnosis that helped her to clearly see that the ideal child, the one preformed in one’s head, is the one rooted in society’s “bogus standards of success” (p.18). When one is to give up the potential child, they are giving up what that child could be, simply based on what society says a child should be. Brown reports it best:

The real problem, Dr. Blumberg said to me ..., lies in our unwillingness to accept that a handicapped life has real value as is—especially if the value requires that you get down on your hands and knees and look for it. ‘Families often do find raising a handicapped child a gift, despite the hardship,’ he said. ‘It creates new relationships, reveals new capabilities. The trick is to give up the idea of the potential child and accept the actual child.’ (p.283)

In this acknowledgement that one does not have to compare their child to the standard Rapp, Brown, Gabbard and Estreich begin to accept their child for who they are and what their spirit brings to the world. The next theme directly relates to such findings.

2. Acceptance of Child

In addition to describing their experiences confronting the precedent with the reception of their disabled child, the authors provide descriptions that relate to how they came to accept their child, as well as their unique way of being. They write about how they came to see the value in

each and every aspect of their child, perhaps even despite their initial resistance to their particular arrival in the world. In their descriptions, they drew comparisons between seeking the inner life of their young child, in the pursuit of getting to know them, as well as uncovering their child's personal ambitions. This theme represents the honest reflections of each of the memoirists in their unique role as a parent and their acknowledgement of the enlightenment they achieved in the raising and being with their child.

2.1 The process of acceptance. Rapp, Brown, Gabbard and Estreich consider their role as a parent to be one that responds to their kin. As the authors describe, this often came with some trepidation and unease, with some more fearful of their own personal inadequacies, while others cemented in the unexpected awe that this particular child came to them. It took Estreich five months following the birth of Laura for him to realize that he loved this little thing. As he states:

It occurred to me only later that, when Laura was in the hospital, I did not yet love her. I may only have been looking after her. Perhaps that is why, looking down at her prostrate in a hospital bed, I was glad she was not Ellie. Perhaps those early weeks were only a down payment on a love we might come to feel. Or I did not allow myself to love her, in order to save myself the pain. Thinking this, I knew it was true; at the same time, I knew, because I *could* think it, it was no longer true. (p.100)

Despite their reserve, each regarded their responsibility to the child as crucial, and ultimately inescapable. In referring back to Estreich's claim, it was clear that he regarded his purpose in being the father of Laura as one that was responsible for caretaking, even before the unconditional love could flourish. Similarly, in response to Rapp's expressed anxieties regarding the raising of Ronan following his diagnosis, another mom in her Tay-Sachs support group asserted, "*He needs you. You are his mother. This is your task, hellish as it might be. You have no choice*" (p.48). Brown and Gabbard express similar experiences—the realization that their particular child needs them, not only to thrive, but simply to survive. It is clear that this responsibility would be overwhelming at the onset, simply because of their surprise and at the diminishment of the expectation, but as Brown states:

But let me ask you this: is what we've been through so different from what any parent goes through? Even if your child is as normal as a bright day, was our life so far from your own experience? More intensive, perhaps; more extreme more often, yes. But was it really different in kind? (p.75)

This quote stands to represent the parents coming to accept their child for who they are—and more so, coming to accept their role as parents to their uniquely given young. This did not occur

right away, for any of the four authors, but was the result of time being spent with their child. As each of the memoirists go on in their narratives, once they dispel their initial shock at their newly acquired “normal” and following the actual work of raising their child, it becomes clear that their child is no longer to be wished away. Rapp expresses this most clearly, as she writes:

It was difficult—maybe even impossible—for me to imagine that Ronan was not, in his own way, perfect, if only because he was living the only way he could. There was a great deal of perfection—and rare innocence—in that. (p.68)

In Rapp’s description, Ronan is not being held to any other standards besides being simply who he was and what he brings to the world. And, of course, Rapp acknowledges the beauty in that—Ronan was accepted for being, with no caveats attached. From there, Rapp and Ronan’s father, Rick, were able to acknowledge and offer unconditional love to the young boy, free from anxieties of what Ronan could be. On similar lines, Brown shares a conversation with a medical professional regarding the gift that would result as a summation of Walker’s acceptance in their lives. After finding out that Walker was diagnosed as cognitively delayed, Brown inquired to Walker’s developmental pediatrician if it would ever be possible for Walker to understand a particular cottage experience that he appears to truly enjoy, or more so, if Brown would be able to explain it to him, with Walker achieving some level of understanding. Doctor Wang, the pediatrician, responded by saying:

‘Not rationally, probably not. But’—he stopped, thought— ‘it sounds like he already understands [the cottage]. [...] The Buddhists say the way to enlightenment, to pure being, is by getting your mind out of the way. I’m not trying to be trite, but Walker already knows how to do that. He is pure being. He may be developmentally delayed, or moderately retarded, but in that way, he’s already miles ahead of most of us. (p.68)

It is here that Brown realizes that for the first time, someone is suggesting that Walker had a gift the rest of the world did not. Acceptance of Walker for Brown was compounded through the expression of someone sharing something wonderful about him, something that was generative and to be valued. This was a novel experience for Brown and his wife Johanna, who were most often met with the deficits of Walker and the *could be*’s of his existence if the right therapies were in place. In this case, it was Walker’s ability to just be that was considered his greatest asset. Based on the way that it was expressed by the pediatrician, this was a gift that others would benefit from as well. In this context, Walker could be embraced. In a somewhat opposing

vein, Gabbard takes an alternative view of August; using philosopher Martha Nussbaum's conception of what it means to be human, Gabbard claims August's presence in the world simply due to

'The fact that [he] has a human body and is the child of two human parents' [...] 'To the extent that we do think of [August's] life as a human life, and I think we are not deceived when we do, it is presumably because at least some of the most important human capabilities are manifest in it, and these capabilities link [him] to the human community rather than some other: the ability to love and relate to others, perception, delight in movement and play. (p.121)

Gabbard perceives August as one who deserves acceptance because he is simply a human. As a consistent narrative told within his memoir, Gabbard transitions from one who fully equates respect and value with intellect and the ability to reason, to someone who broadens their conception of acceptance. As Gabbard came to know August, he came to accept him and came to accept an alternative perspective of embracing another.

2.2 The unique being in the now. As Rapp, Brown, Gabbard and Estreich came to know their child, they came to accept and uncover the value of their child. This required an openness that afforded each of the children the opportunity to just be, as they are. For instance, when August was two Gabbard discovered a favoured past-time of August: he would load August's Mulholland play surface with multiple plastic and metal balls, and around the stander on the floor would position some large metal bowls to catch the balls when they fell off the tray. August would then play as follows:

August's left hand, the semi-usable one, would feel about on the surface of the tray before him, probing to capture a ball. When he would finally pick one up, he'd bring it to his mouth and sample it with his tongue and lips. This was his way of experiencing the world. (p.50-51)

Gabbard does not suppose that August plays ball according to the standard method of conventional throwing and catching, or even a particular rote method, but rather takes the time to see how August wants to conceive the ball himself. August's own way of being in the world has him using alternative senses in addition to the conventional form of touch, such as tasting the ball, to acquire a sense of it. In doing such a thing, August was able to manipulate the object before him in his own unique way—the way that accords with his own ambition. Gabbard puts it most eloquently: "August had become a devotee of the senses. Cultivating whatever gave pleasure became the chief business of his life. He did not know of any occupation that was more

important” (p.90). Gabbard provided August with the opportunity to just be, and in doing such a thing, came to know and appreciate the child within their own self and their own biography. This affords them a context that allows them to appreciate their behavior as it is. Similar to Gabbard, Rapp, Brown and Estreich did not necessarily have an explanation for why their child perceived and experienced things so differently than the conventional, but instead simply came to accept the one certainty that they did have: that their child liked to do things the way they liked to do them. They came to understand that each of their children had their own secret world, a world that they would not necessarily understand, but instead could allow to happen and make their own meanings of. In reference to Laura’s “delayed” use of speech, Estreich hypothesized that

As with appetite, the switch lay within Laura. It seems, sometimes, that she holds out on us, perversely, in order to remind us she’s not a machine to be programmed. [...] Sometimes I think she’s as weary as I am of developmental charts, of the incessant, nagging whisper to advance, advance. She keeps her counsel; she takes the next step when it suits her. Until then, her refusals are concise, deliberate, more expressive than any word. (p.142)

Interestingly, Estreich does not accord Laura’s gradual acquisition of speech as a result of her diagnosis of Down syndrome, as any professional likely would, but instead ponders that it is a result of Laura’s ambitions to reveal something greater to those around her—a lesson, perhaps. Brown sees Walker’s ambitions in a similar way:

For a boy like Walker, an ornament on a Christmas tree could be the Ark of the Covenant: it glitters and snatches his attention, and the shred of care and detail and imagination that went into its making is refracted from its designer to me, or anyone else who can take the time to look at it, through Walker. If I pay attention long enough and sit still long enough to think about it, if I am daring enough not to scurry along to a more ‘productive’ or distracting activity, the idea of hanging a trinket on a tree, a memory on a branch, an ancient pagan ritual, rises into fresh view again. Walker is a lens [...] through which to see the world more sharply. Walker makes me see the ornament for what it is—better still, for what it could be, for what it might be. *Look here, Pa*, he says, *see what you missed. All you have to do is slow down. Let me show you how.* (p.242-243)

Walker’s fixation on each and every ornament as their family attempts to decorate their tree for Christmas exposes Brown to the idea that there is something beautiful to be seen within each and every object being hung; if that was not the case, why would Walker be so enamored with each of them? As well, Walker reveals to Brown an even bigger ambition that perhaps Brown should take on himself: to slow down and think about what you are doing in order to reveal the nature of

the action embedded within the moment. Brown takes his perception of Walker's inner life and creates a lesson for himself from it, just as Gabbard and Estreich do in the above examples from their memoirs, without being presumptuous. These authors express that perhaps there is something to be learned from the unique inner (and outer) lives of each of these individuals.

2.3 The child in the world. While discussing how they came to accept their children for their unique senses of being, Rapp, Brown, Gabbard and Estreich began to understand their role in uncovering the benefits that their child brings to their worlds. This typically resulted in a sense of enjoyment of the time they were granted to spend with their children. Brown referred to these moments as ones full of "unstoppable pleasure" (p.67). Being able to see the happiness that overtakes their child when they are with their sister, as in Brown's case (p.67); August playing sports unconventionally alongside his father and the uncontrollable laughter sprouting out of him, as in Gabbard's case (p.51); and listening to stories told by Laura simply based on the fact that they matter to her, as in Estreich's case (p.252). It was each of these unique individuals' actions and behaviors in the world that came to display their value within it. They were adding benefit to the lives of those around them, directly opposing societal beliefs reflective of the tragic narrative of disability. To contextualize, Rapp asserts:

As tragic as the situation appeared from the outside, the inside of our lives was often blissful, despite the daily very real dread about what was happening as this ridiculous disease spread across Ronan's brain and shut down his body. In the morning we lifted Ronan from his crib and kissed him. There was joy. We laughed. We lived. I took him hiking and rubbed his fat feet in the dirt and lifted his face to the juniper-scented breeze. He went on road trips, to parties, coffee shops and restaurants. He was our companion, our child, our beloved. (p.24-25)

The memoirists approached their children with an openness and a willingness to allow them to be; they allowed them to be who they were without the pressure of measuring their child's effort to anything—normative standards, developmental milestones, among other indications of success. In doing so, they themselves were afforded the opportunity to be challenged into betterment by their children; that is to say, each parent opened themselves up to the benefits that their children would bring to their lives. Rapp, for instance, reflects on the laughter and present living Ronan offered her; Gabbard, on the other hand, discusses the spiritual journey he embarked on following the birth of August. He begins the memoir by referring to himself as a

former self-proclaimed atheist. Later, he describes his shock at seeing God in August, as he states:

There were a few times, as I described, that I experienced the sensation while looking into August's eyes that I was staring into the face of God. The spirit was within him, and my glimpsing it there served as premonition of recognizing it in myself. At the time of his birth I didn't know that he would develop into a beguiling little fellow, that he would elicit great love from us and from many other people, or that like a Yaqui shaman he would introduce me to a separate reality. And I didn't know that this separate reality was actually the world of my own heart, my capacity to give and receive love. (p.221-222)

Aside from the manifestation of the need to reconsider one's possession of spirituality, Gabbard makes it clear that love appears to be the greatest gift and value that each of the four children of the study allocate to their parents. Not only is this the capacity to give love but also the capacity to stimulate love from those around them. Brown shared a similar sentiment:

But like many other CFC children, he had changed lives, mine as much as anyone's—deepened and broadened me, made me more tolerant and durable, more ethically dependable. He had given me a longer view. That felt like some form of evolution too, a positive ethical evolution, albeit not the kind modern genomic science tends to measure. (p.167)

The value that these children have bestowed on their parents is evident within the ways that Gabbard and Brown speak of them. It appears that each of the parents achieve some sort of enlightenment or betterment as a result of this one particular child being present in their lives. Despite the unease and trepidation that each of the parents experienced following either the unconventional arrival of their child or the misery preceding diagnosis, as they came to get to know them, they began to uncover the value of their presence within each and every one of their lives. Estreich articulates it well:

How, then, to tell Laura's story? How to explain the way my vision had changed? Because by then, Laura had long been one of us, a fully vested member of our family, and the happiness she brought us was real, without dilution or asterisk. She was part of our story. Her trisomy had complicated that story, from heart surgery to speech therapy. But her genetic beginnings—on paper, far less promising than Ellie's—had resulted in no less happiness. The genome is the beginning of the story, not the end. (p.238)

This idea of newly formed perceptions regarding the value of their children leads into the third theme relating to how parents come to value an alternative way of experiencing the world and an alternative perception of both time and space. This stature is marked by imagination.

3. Imagining A Life Together

Throughout their memoirs, Rapp, Brown, Gabbard and Estreich discuss how having a child with a disability has offered each of them the unique opportunity to invent their own story. These stories may describe how they live their lives, counter to and alongside typical narratives; they may function as a means of coping with trepidation in moving forward; and, most importantly, they are always employing imagination to suppose ideas of how the world could be, rather than how it currently is. It appears that in the act of creating a life story, each of the parents in study is able to meet, respond to and reach their child. These findings point to the cruciality of imagination in each of these memoirists' narratives.

3.1 Invoking imagination. In each of the accounts, Rapp, Brown, Gabbard and Estreich oppose most of the formalized and temporally normative developmental standards. They each comment on the restrictiveness of normality and the difficulty of measuring up to seemingly concrete standards of success that typically initiate acceptance within the dominant society. Interestingly, Rapp equates society's expectation of striving for achievement with the mainstream desire to transform oneself. She writes, "We are all trying to escape our existence, hoping that a better version of us is waiting just behind that promotion [...] Everyone needs to be pursuing something, right? Otherwise, who are we?" (p.71-72). Rapp questions what it means to be someone who is unable to succeed, or transform themselves into betterment, such as someone like Ronan. Yet, she provides a simple answer to what seems like a difficult question: "How about, quite simply, people? How about human?" (p.72). It is Ronan that teaches Rapp to expand her imagination regarding what it means to be human and in the world. His presence on earth indicates to Rapp that people need the freedom to be people, as all cannot measure up to the standards of success which society deems as pertinent. Imagination allowed Rapp to pull the veil off of her eyes, in relation to the significance that society imposes on certain things, such as development, in order to live honestly. She would not be able to teach Ronan to read, write, walk and talk—rather, he would teach her to be open to what could be. In this sense, the use of imagination is a cure for her initial well-meaning flaw of ignorance based on societal expectation. A similar situation occurred for Gabbard, where August was the antidote to Gabbard's quest for reason and explanation:

For those who did come to know August well, he was a monster in the former sense [monster as something incomprehensible and awe-inspiring, a wonder or prodigy]: he was inscrutable. This inability to fathom him, to solve his mystery, eventually would bring to mind questions not so much about him but about the nature of meaning itself. Looking into his eyes represented gazing directly at the mystery of the universe [...] To the extent that he would provoke larger questions, he became a child signifying the unfathomable cosmos. This is not to say that his disability conveyed a meaning but rather that it disrupted meaning. He exposed the limits of meaning, the illusory nature of the meaning-making enterprise. His disability compelled me to stand in awe of everything, of a universe stripped of the significance that we human beings impose on it. (p.126)

August's arrival in the world prompted Gabbard to reconsider all that he thought was true. It was as if, following August, Gabbard was born anew. Instead of approaching August's life with knowledge and reason like he did all other things, Gabbard had to employ imagination. He communicates why he did so as follows:

A scientific, empirical description turned August into human rubble, a car wreck that had happened in the delivery suite, but imagination allowed us to move the medical diagnoses to the curb so we could reach our boy. In our minds' eye he wasn't all that different. He was August, just one member of a quirky family. (p.90)

Thus, in order to come to know August and inevitably come to accept him, Gabbard would have to halt his complete and firm hold on how he had envisioned the world so far. Estreich experienced a similar thing with his intentions to move away from the dominant tragic narrative of Down syndrome. He agrees that scientifically, Laura does have an extra chromosome—an extra twenty-first chromosome, specifically, indicating Down syndrome. But he opposes the sharp division between typically developing children and children with special needs. He says:

You CANNOT write a story about a child with Down syndrome without taking account of the existing story, the way the story of the diagnosis is told. That story, as I found, boiled down to ideas about likeness. In what way is a child with Down syndrome like, or not like, other children? This was more than an academic question; for me, it was a question that destroyed the distinction between the academic and personal. It was the question that troubled me after Laura arrived: my daughter was of us but did not seem to be like us. That was the central problem I had to negotiate as a parent, and it was a problem that demanded imagination and time, not research and data. I came to see that the perception of Down syndrome, from the beginning, has been dominated by false likeness, by a literature that sounded scientific but was, instead, an accidental poetry: people with Down syndrome were 'like' Mongolians, who in turn were more 'like' nonhuman animals. I saw this false poetry reconstituted in the stereotypes present today

[...] and in the habit of referring to people with Down syndrome as a uniform group, of condensing them to a single type. (p.281)

Estreich came to be exposed to some of the flaws in what is conveniently cast as true in society. He traced the lineage of the development of Down syndrome to the place where it first came in existence; from there, he was able to compare conceptions of the marker from the past into the present. Doing so afforded him, in conjunction with his daily experiences of Laura, the opportunity to shy away from convenient prescriptions of the syndrome as he realized these prescriptions were just descriptions that transpired alongside diagnosis. Going forward, Estreich committed to the employment of his imagination for envisioning Laura, in the present and in the future; he could no longer depend on the false descriptions of Down syndrome that limited Laura into a single and, in his eyes, artificial category.

3.2 A different kind of parenting. Rapp, Brown, Gabbard and Estreich all remarked on their transition from future-building parental practices, to practices reflective of in-the-moment parenting strategies. The clearest example comes from Rapp, where the options for the employment of parenting strategies for Ronan were limited. As Rapp asserts: “The dreadful hitch in this otherwise middle-class and privileged domestic snapshot was this: Ronan would never benefit from any of Rick’s and my efforts beyond what he received *in the moment*” (p.15). Everything for Ronan was experienced in the present—immediate touch, taste, sight, sound with no cognitive recall. He was unable to store memories, whether joyful, fearful, terrifying or liberating. He was only able to receive direct experience that ended as quickly as it began; Rapp remarked on experiences such as “a feather brush[ing] against a cheek, a startling sound, the surprise of a new sensation” (p.157), but then it would be forgotten. Thus, Rapp and Ronan’s father, Rick, were to parent in the present; they were to feed him, brush his teeth, make sure he was clean, warm and well rested. This required a stillness of sorts and the practice of imagination, to embrace the alternative day-to-day experiences between parent and child. On one of their mother-son hikes, Rapp articulates her alternative relationship to time in parenting quite eloquently:

The snow stopped and spring flirted with Santa Fe again. I took Ronan for a walk along the arroyo path, his path, where the snow-touched mountains were visible in the near distance, flanked by the purpling hills. [...] I stopped for a moment and gently removed his hood. I let the wind ruffle his red-blond hair and I looked at his sleeping face and I rocked him for a bit in the sun. We kept walking into a tunnel strewn with

dry leaves where both our shadows disappeared and we were alone. I stood still and listened to his breath and mine. I felt a momentary flash of peace, a great still pause. T.S. Eliot's "still point of the turning world," and of course this terribly tender love, and I thought, *This is all I have to give*, and I tried with all of my strength to pass that feeling into Ronan, and then I thought, *Remember this*. (p.93-94)

Similar to the ways in which Ronan is to be parented in the present moment, the same goes for Walker. When looking at a picture of Haley, Walker's older sister, reading to him while they were up north, Brown comments on the way Walker is looking at the book and revelling in the experience. First, he states that it appears as though Walker is reading each word, riveted by each syllable, chunking of words and expression, when in reality, Brown is not even sure if he understands any of it. As well, Walker's huge smile appears to reveal his happiness to simply be with his sister and grasp her affection. Brown states, "He has become the moment and it has become him, because he has nothing else to be. Walker is an experiment in human life lived in the rare atmosphere of the continuous present" (p.79). One would be remiss without mentioning Gabbard and Estreich as well, who both comment on the present-orientation of laughter and fun. When reflecting on the ways in which Gabbard and August used to play ball, Gabbard shares:

'Goal!' I would yell, and he would laugh. This had become our sport, our way to play ball together. It wasn't that he knew what the word *goal* meant, he just liked the percussive chime of the ball hitting the bowl and me shouting the word. [...] "Goal!" I would cry again, and at this he would laugh very hard. I would begin to laugh to because he was so amused, and then he would laugh even more. I loved watching the way delirious joy overcame him, the manner in which he would throw his head far back, the way his body convulsed, his eyes half closed and his mouth agape. (p.51)

For Gabbard, this laughter was a result of the spontaneous moment—Gabbard would yell "Goal!", August would laugh, Gabbard would laugh and then they would go on. There were no thoughts of the past (what should have been) nor thoughts of the future (what is to come). The alternative form of ball play that they conjured up together was something that was shared between them, in the now. To provide one more example, Estreich discusses how he acquired minor fame on the playground of Laura's preschool. He talks about how, for the kids who sat on the swing with Laura, he did the full-on clown routine. Estreich writes that he would pretend to get knocked down by the swing, then do somersaults and return covered in bark chips. He would then pretend to take naps until the kids would wake him up with their screaming and, finally, end his show with an exercise in pretending to misplace the children. Of course, the fun occurred in

the moment with all of them participating and laughing and carrying on, but at the same time, Estreich's motivations were a bit more calculated:

It is the way I play with children when I am not depressed, but it is also a calculated game of inclusion. Since it is about momentum and silliness and screaming, and not, say, numeracy, Laura's deficits become temporarily irrelevant. Besides, I'm happy to embarrass myself for her sake. If the kids associate Laura with Fun, Laughter and Incompetent Clown Dad, that's fine by me. It beats the hell out of Weird-Looking Kid Who Can't Talk. (p.248)

The temporal experience reflected in this example is both present and future focused. First, it is present because, similar to Gabbard, laughter and fun is momentous. However, Estreich is being deceptive in a sense with his motivations as he intends to create experiences for Laura's peers indicative of Laura being coupled with fun and laughter; this is future oriented. It is not to say that any of the authors in study completely negate the future in their parenting of their child—they have just been afforded the opportunity to see some of the myths inherent in a future-building approach.

3.3 An alternative vision of time and space. In their memoirs, each of the authors recalled instances in which they seemed to be inventing a world together with their child. As mentioned, due to Ronan, Walker, August and Laura's often exclusion from the linear temporal framework and the ideologies that were present within it, they and their parents had no choice but to imagine and create their own space to be. As Brown says, "I once came across a blog on the internet written by the father of a disabled child, and he discussed such matters. 'A disabled child teaches you to make your own rules,' he wrote" (p.101). This space, typically metaphorical but manifest in the physical world, was marked by a celebration of their presence within it. Together, they created spaces where all were welcome, regardless of atypical experience and without apologies. A great example is shared by Brown when describing Walker's love of going for walks while in the stroller. Together, the two of them would venture out into the public streets and "chat" about all the sights they would see. Pretty quickly, Brown noticed, that people had a way of looking at them—some looked away quickly, few smiled at them, and many appeared horrified. In the real world, Walker appeared to be a spectacle. But as Brown asserts:

The staring used to bother me. [...] I have known what it is like to be stared at, to be an object of fear and pity and even hatred. I hope Walker can't see it; he seems to ignore it, and gradually he taught me to ignore

it as well. These days we strolled the boulevards as if they were ours. Walker has made me see how many of the rules we live by are simply made up. (p.105-106)

Together Walker and Brown assert themselves in the world; this requires a sort of invention of space where they could be welcome just as much as anyone else. A separate but similar example from Brown's book further illustrates this concept; near the end of the memoir, Brown visits L'Arche in France, a community built and sustained for the disabled and for those who care for them. Brown summarizes the community structure as follows:

No one at L'Arche talked about integration, the way staff do at conventional homes for the disabled: this community existed for the disabled and made no pretense that residents eventually would be part of the 'normal' community. People like me were the outsiders here. There was a routine, a structure, a community of individuals, and their lives counted for what they were, no added value required. (p.199)

Brown asserts that L'Arche represented the world of the residents—it possessed its own set of standards, its own pace of life, and it was simpler and less serious in comparison to Brown's world. The community was designed according to principles reflective of a non-hierarchy; residents and assistants lived side by side, as equals. Again, this was non-representative of Brown's experience. During his visit, he met Jean Vanier, the founder of this widely known, internationally renowned charitable organization. In their discussion regarding why Vanier dedicated his life to those with intellectual disabilities, despite not having a diagnosable disability himself at the time, Vanier responded as follows, as reported by Brown:

'There was something in me that wanted a commitment to people' [...] 'In the beginning [I] was still in the very traditional thing of doing good for the poor [...] But then it switched: [I] realized [I] was benefiting. After that [I] wanted to be a voice for people who had no voice. [I] quickly discovered that the simple life, living with Raphael and Phillipe, was satisfying.' (p.202-205)

And so, over the next several decades, the initial venture of a home comprised of simple co-existence attracted attention, garnered donations and expanded internationally. Today (reported by Brown in 2009), L'Arche is "a village where we meet each other. We celebrate life" (p. 209). In summation, Brown's visit to L'Arche exposed to him a model of how the world could be—an alternative way of being outside of the requirements of normative expectation. To Brown, L'Arche acts as a symbol that exposes how another type of community, another approach to community and, ultimately, how another vision of the world is possible.

3.4 Sharing stories. Rapp, Brown, Gabbard and Estreich all comment on the importance of sharing constructed narratives to make their experiences known. Each believes in the potentiality of disclosure—for Brown, this meant travelling across North America to meet other parents of children diagnosed with cardiofaciocutaneous syndrome and garner their experience (p.112-157); for Gabbard, this meant protesting a visit from the popular genetic engineering proponent Peter Singer at his place of work (p.115-124); and more broadly for Estreich, this meant telling the individual story of Laura to oppose the common story of Down syndrome (p.280). As Rapp states:

We needed new words and a new language, and it could be only created through discourse, which could only happen between people using language to make their experiences known. Enter art in its purest form: mucking up meaning. Disrupting our worldview. Redescribing story, Ronan's story—his path, his myth—could blaze new pathways of understanding not only for me but for others. (p.53)

By putting the efforts in to share their experiences and tell their stories, each author expanded the possibilities for being. The disclosure of experience showed that there was not only one reality (or narrative) for all to reside within. As Rapp stated, it is the function of the story to disrupt and challenge our worldview. Estreich conceptualizes the telling of Laura's story similarly:

I was often asked why I'd written Laura's story. It is not necessarily the first question a writer wants to hear, but from this vantage point, it's easiest to say that I wrote the book to fill a hole. For many if not most people, 'Down syndrome' names not a nuanced, complex reality, but an absence—a warm and fuzzy one, perhaps, but an absence all the same. Putting Laura's story out in the world might strip away a bit of the fuzziness, if not the warmth. Besides, writing was what I'd always done; if I didn't write, I didn't know what I was. So the book, I hoped, would fill a hole in the world, and in the meantime writing filled a hole in my life. (p.278-279)

Estreich attempts to offer Laura's story to expand the reader's imagination of Down syndrome. He makes the case that there is an existing and pervasive narrative of Down syndrome in society, one marked by tragedy with a caveat for explanation regarding expectation (i.e., it is not what can one expect from their child, but rather, what can one expect from their child with Down syndrome). His hope for Laura's story is to expand upon any individual's given expectation of the diagnosis of Down syndrome. On another note, in the above quote, Estreich discusses that prior to the filling of the hole in the world, the act of writing would fill "a hole in my life" (p.279). In grappling with their grief at the letting go of the potentiality of their child based on

pervasive narratives of developmental typicality, Rapp, Brown, Gabbard and Estreich all express that writing was useful as a means of coping in the now. For Rapp, this was especially true, as she was able to construct a space for herself to reside in, amid all the grief and heartache that went alongside Ronan's diagnosis and future. As she stated:

But what does writing do? It was not saving Ronan in the literal sense (if only if only if only) because nothing could, and it wouldn't save anyone else and it certainly wasn't going to save the world. What about my intentions? Was I trying to 'save' Ronan, as if turning his story into a project will make the situation less 'true' and therefore easier to bear? Yes and no. Writers scribbling in the midst of grief have noted the ways in which writing about the experience from the inside creates something new, namely, a safe or safe-ish place to rest. A net, a landing point, a dock from which to view the turbulent and troubled water without having to wade in it every moment of every day. In a word: relief. (p.124)

Rapp used writing Ronan's story, and ultimately her story, to assist in the daily experience of raising Ronan amidst his inevitable death. To her, writing their story was not about increasing awareness of Tay Sachs disease or reaching out to others for their perspectives on the experience, but rather, writing gave her the space to simply be. In the construction of such a literary aesthetic, she was able to grapple the weight of both present and future.

4. Reclaiming the Mystery

As each of the memoirists approach their conclusions, it appears that they come to a similar reckoning—that there are many ways of being human and that there is value and insight embedded within each of them. In this theme, Rapp, Brown, Gabbard and Estreich all discuss how their child's unexpected and unconventional arrival has resulted in them loosening their grip on the dominant societal features of the Western world, including the need for explanation, future-orientation and control over nature. It is due to their child that they realize that control is an illusion that no one is able to possess. In saying this, the authors commit to a widening of the single narrative of disability to initiate an accommodation of the multiple, unique stories that each individual possesses by simply being in the world. They do this by sharing their own respective narratives. This theme concludes with the idea that people of all kinds should be afforded the gift of mystery over their futures; it should not be something that is laid out for them based on diagnoses or categorization, all reflective of the single story of disability.

4.1 Departing from singularity. When each of the author's children were diagnosed with their disabilities by medical professionals, they were met with the narrative of tragedy. The deficits associated with their disorder were disclosed, their unconventional futures were foreshadowed and their potential for success was taken from them. Rapp discloses that she has trouble conceptualizing this removal of worth, as she says:

To be valuable, [human beings don't] need to have so-called potential, whatever that means. Earning power? Advanced degrees? Exciting inventions in their pockets? Beautiful bodies that might sell products and have the added value of boosting the economy? And they lived, even though their lives were truly the stuff of other people's nightmares. Their stories mattered, even if we never heard them. Ronan's life mattered, even though I was the one telling his myth, even though his brain was devastated, his body doomed. (p.233)

Rapp questions why value is associated with the individual who is "able" while rendered away from the individual who is "disabled". Gabbard nearly answers her question from his own memoir as, when he is talking about genetic engineering proponent Peter Singer, he says, "Babies with birth defects are his main focus because infants with impairments, he believes, will be inherently worse off than those unimpaired. Their lives will be permeated with suffering and therefore will not be worth living" (p.100). Gabbard talks about how Singer's philosophy fits well within a society that equates personhood with autonomy, self-reliance and individuality. Similar to Rapp, both ideas reflect the single story of disability—that it is a calamity and something that should not be desired, that all these individuals are suffering. Rapp makes the case that Ronan's life still matters, even if it appears to the outside world that his situation is tragic. As Gabbard asserts, it is this framing of disability as tragic, embedded with this idea that all who are disabled are suffering, that situates disability as a problem in the world. Continuing, Estreich makes it a point to showcase how this pervasive ideology is embedded in both the medicalized and layman's understanding of Down syndrome. When Laura was born and in reception of her formal diagnosis, he and his wife, Theresa, having no experience with Down syndrome, did research to find what they could expect from their daughter. He came across many lists, some written in the past by John Langton Down—the developer of this namesake syndrome in the 1850's—to some written very recently. But it was not until later in Laura's life that Estreich critically thought about such reading materials:

In general, the more recent the list, the more accurate and neutral it tends to be. The best make the developing individual central, not a footnote. But even when these criteria are satisfied, even when the depressingly usual exaggerations are set aside, there are deeper limitations inherent in the form. *Every* diagnostic list, by definition, sets the child with Down syndrome apart. [...] But in the end, a parent dreams of a time when the divide does not exist in the first place; when we do not need to say *a child first*; when every child is seen as inhabiting a continuum of human abilities; when the idea of ‘normal’ is used in a strict, statistical sense, and not as a divisive, emotionally loaded label; and when that label is invoked only to help the person it describes. These are, typically, insights that parents of disabled children arrive at, simply in order to stay sane. But they are not yet generally accepted. (p.178)

The issue with the diagnostic list, from Estreich’s perspective, is the story that is associated with it; one consequence of this is a sort of “character sketch”, where one individual with Down syndrome stands to represent all individuals with Down syndrome, while another consequence is the projected future. What connects these consequences is the explanation and expectation of Down syndrome without the caveat of an individual person embedded within. As Estreich says, “They do not describe themselves; they are only described” (p.179). Thus, again, one story stands to represent all, with no credence given to the multiple, individual lives.

4.2 Unique journeys. Despite society’s emphasis on the single story of disability, Rapp, Brown, Gabbard and Estreich commit to the idea that each of their children deserve to have their own individual story told. In revisiting Estreich’s difficulty in separating Down syndrome’s inherent method of lumping together all its affected individuals into one structural category as described in the previous sub-theme, later in the story, he comments on the individuality of Laura:

Laura’s diagnosis is common, but her identity is singular. For this reason, there are limits to what any one child can tell you about any other. Because a family’s happiness—however defined—is the product of many factors beyond a child’s particular diagnosis, an incalculable arithmetic of old patterns and chance events and family circumstances and community and culture, it is not possible to say that every family that receives a child with disability will be a happy one. It is not even possible to say that a child’s disability will, without question, be the determining factor in a family’s future. It is, in my experience, less millstone than butterfly’s wing. (p.280)

As reflected in Estreich’s account, Down syndrome does not result in a singular future or endpoint. Each individual, diagnosed with the syndrome or not, will have their own unique experience in the world, as there are many factors that affect one’s day-to-day world beyond the

diagnosis, including, but not limited to, as Estreich states, “chance events, family circumstances, community and culture” (p.280). One cannot associate Down syndrome with a singular forecast. Perhaps this perspective is compounded by Estreich’s previous experience at the 2006 British Columbia Conference for Down Syndrome, headlined by neuroscientist, Doctor William Mobley. Interestingly, however, it was not Dr. Mobley’s presentation that had Estreich realizing that comparing individuals diagnosed with the syndrome was futile, but rather, it was seeing all the attendees of the conference with their respective families. Estreich reports:

I looked around the ballroom. Seeing the faces around me, I saw the best reply to Down’s mistake: the children looked like their parents. They looked like each other too, but it was clear that their true brothers and sisters were theirs by blood, not diagnosis. They were, to use Down’s phrase, a part of the great human family. On my most hopeful days, on the days when my own molecules are up to speed, I think more people will come to share their perspective: that the diagnosis will be a footnote to individuality, and not the other way around; that stories of ordinary lives will come to replace the tragedies and fables still accepted as truth; and that Laura will live in a world where she seems as ordinary to others as she does to us. (p.261)

Again, Estreich, Brown and Gabbard advocate for their child’s individuality because they have had the advantage of knowing them and their capacity, despite the often-tragic story that accompanies them in the outside world. One final example of how comparison is futile comes in the form of Rapp’s perception of healing for Ronan. Near the end of her memoir, Rapp discloses how healing for Ronan would be different than most people’s conception of healing:

Healing, for Ronan, would not mean the radical healing of his physical form. It might mean instead his full acceptance into community, into family, not the fixing of his physical body. Healing might mean no prayers for a miracle but prayers for his peaceful, albeit short, life [...] Healing for Ronan might simply mean people meeting him and experiencing his uniqueness without thinking *He’s blind, he’s paralyzed, he’s deaf, he’s retarded* when he was all of these things. As Becky, another dragon mom, pointed out to me, our minds are littered with these classifications that block us from seeing the beauty of individual souls housed in particular bodies. (p.149)

As Rapp mentions, healing is typically associated with alleviating some sort of physical ailment, but in Ronan’s case, healing would mean something different. Rapp consistently mentions in her memoir that she would never wish Ronan to be anything but who he was; they were never going to run away from him or wish for perfection. In this instance, all they wanted for Ronan in terms of healing was acceptance of his individual being held within his unconventional body. It is here

as well that the single story of disability is slightly dismantled by the full acceptance of Ronan's individuality, despite the narrative of tragedy that may be associated with his Tay Sachs diagnosis.

4.3 Multiplicity of humanity. The authors all remark on the ability of their children to teach them things. A major lesson that Rapp, Brown, Gabbard and Estreich speak about is how their child shows them that the world belongs to everyone. Ronan, Walker, August and Laura all have a story compounded with their diagnosis—regardless of this, however, each individual, consciously or not, stakes a claim on their place in the world. To Ronan, it does not matter that he will not live long; to Walker, it does not matter that he does not communicate verbally; to August, it does not matter how he can move or not move; and to Laura, it does not matter if she possesses distinctive features of Down syndrome—what matters, rather, is that they each live or lived. Each author discusses how their child displays their own individuality and their own way of being human. Rapp, for instance, states:

Who counts in this world and how much? Who does the deciding? Who has 'potential' (that is value) and who does not? [...] What did matter was love, given freely and without agenda or expectation. I loved Ronan, this unique person, this human being, without thought to what it might lead to for me, what it might say about me, or what it made others think about me. [...] This was *my* son, my baby, my 'handful of earth', sitting on my lap, cooing and squawking. (p.234)

Rapp makes it clear that she loves the unique individual that Ronan is unconditionally. Perhaps that is one clear illumination of the beauty in multiple ways of being—it expands our capacity for love. Surely for Brown, this is also the case:

Genetic tests are a way to eliminate the imperfect, and all the pain and agony that comes with that imperfection. When Walker was an infant, before he lodged himself in my heart and mind and memory, I spent part of every day furiously wishing that a test had been available, wishing that we had had a choice in the matter of his existence, for his sake and our own as well. Now that I know Walker, I am relieved there was no such test, that I didn't have to face the ethical dilemma it may soon present. Because on his good days, Walker is proof of what the imperfect and fragile have to offer; a reminder that there are many ways to be human; a concentrator of joy; an insistent nudge to pay attention to every passing mote of daily life that otherwise slips by uncounted. A test avoids all of that, for better or for worse. (p.180)

Like Rapp, Brown does not want to change his boy, or else he would no longer be Walker, or as Brown refers to him, *the boy in the moon*. Love grew between them, and it was love that

expanded Brown's capacity for serving Walker and seeing the beauty of his individual being. Gabbard and his wife, Ilene, quickly discovered the beauty that was in August as well, despite how the medical field initially came to describe the boy. Gabbard writes:

Had we parented August with only the doctors' and therapists' descriptions to go by, we might have thrown up our hands in despair. But we knew that August was more than a smoking heap of terrible conditions. Because we saw that he was a happy and lively being, we didn't let the medical terminology or bioethical stereotypes govern our thinking about him. (p.89-90)

The medical terminology or bioethical stereotypes that Gabbard is referring to compare August to the norm and therefore embed him into the tragic narrative of disability. But Gabbard and Ilene saw through that; they were able to see the boy and his uniqueness through his impaired body. And in doing so, they saw the beauty in difference. To conclude, Estreich also comments on the profound beauty in humanity's many forms:

I knew nothing about Down syndrome except that it was bad, and that it means Laura was different from me. I no longer believe the first—Down syndrome is simply Laura's way of being human. As for the second: Laura *is* different, but the differences are superficial. This may seem an odd assertion, since the extra chromosome pervades her, and its effects texture our days. And yet these altered forms, eye and face and word, have come to contain and absorb what I know of love. Or love learned to alter itself, to accommodate the forms. She is no less my daughter, no less a person, for having an extra chromosome. (p.263)

Estreich's quote provides a clear summation of each of the four authors' transition to an acceptance of multiple ways of being. Perhaps prior to their child's arrival, they acted within a situation of ignorance, where their understanding of development was a normative one. For many of them, this enlightenment did not come until after they came to know their child and claimed to see their individual value in the world. It was coming to accept their child that expanded the ways in which Rapp, Brown, Gabbard and Estreich came to see the value in multiple ways of being.

4.4 Our desire to control. To conclude this theme, it is important to discuss how Rapp, Brown, Gabbard and Estreich seek to reclaim the mystery of each of their children's presences and futures. The reclaiming of the mystery and value of one's presence has been detailed in earlier sections, but this sub-theme is particularly interested in advocating for the future to be more open-ended by dispelling our need for control. Of course, this theme is not explicitly

dictated within any of their four memoirs, but rather, underlies their desire to expel—what appears to be in some instances—a tyrannical need for control in society. Rapp, Brown, Gabbard and Estreich each write about how they themselves have had to deal with the shattering of the illusion of control in their lives. To explicate this concept, Gabbard describes in his memoir how his efforts to control fate before August did not come to fruition:

Ilene and I took all of the measures expected of enlightened parents-to-be living in a technocratic society. In preparation for this birth, we underwent genetic testing before conceiving, and Ilene had an amniocentesis early in the gestation period. All of the test results pointed to healthy development. Having read *What to Expect When You're Expecting*, Ilene stopped drinking coffee and alcohol, which she had never done much of anyway. Prior to and during the pregnancy she didn't take any medications, and before becoming pregnant she had followed the recommendations of taking folic acid supplements. (p.14)

Gabbard and his wife desired a particular outcome, a healthy baby; to maximize their chances, they heeded all precautions prior to conception, the gestation period and, of course, the birth. Unfortunately, despite this employment of reasonable preparation, during delivery August suffered a “hypoxic-ischemic brain injury”—in plain language, he was deprived of blood and oxygen as a result of an unexpected medical error. This was not projected to happen—not to mention, Gabbard and Ilene likely never thought that something like this would happen to them. Rapp describes this well-meaning culturally pervasive sense of ignorance eloquently:

We all want to believe we're on solid ground and that we won't be the ones to tumble into the mud. But we will. [...] We all want to feel in control of our destinies, our wishes and desires; we crave the illusion of control. (p.36)

Throughout her memoir Rapp consistently writes about the American ethos of self-improvement and transformation and emphasizes the systemic befuddling when situations occur that defy solutions. Despite our attempts to master our futures, nobody is immune to disease or sickness or any other catastrophic event. These authors have been confronted with such instances, instances that perhaps, for some, go against nature and the advertisements on television about the miracle of birth and the unadulterated joys of parenting. Gabbard conceptualizes these expectations and projections as evidence of the modern globalized world's roots in the European Enlightenment of the eighteenth century. To him, ideas of progress, rational thinking, knowledge and intellect would solve the world's problems; an explanation could be acquired for anything, and the world could be stable and would have order. Nonetheless, he discloses to the reader early on his

transformation from “enlightened thinker” to someone who questions enlightened “thinking”. This was because of August. He describes the transition simply:

Overall, I continued to believe [Aristotle’s teleological theory] that the unexamined life is not worth living. But blebs of doubt had begun forming in the glass of my worldview, and eventually secure assumptions started to give way to questions for which no answers seemed possible. [...] Like a strong wind at my back, the force of these questions began to propel me forward in a new, unexpected direction. I found myself increasingly grasping for something. Were I to miraculously receive all the answers about August’s birth, find the empirical truth, the scientific basis, would this really make a difference? That my boy remained nonverbal, non-ambulatory, visually impaired, and diaper-reliant was a reality I had to face. But science and reason couldn’t help me do that. Because they provided cold comfort, a bigger problem was at hand. I began to suspect that modernity—heir of the Enlightenment—this brave new world, was hollow at the center. There was no *there* there. It offered nothing but incessant change and vague promises of a better tomorrow. (p.72)

In revisiting Rapp, modern society has us seeking to satisfy the desire to possess certainty and to exercise control, but Gabbard reminds us that there are holes in such a philosophy, and each of the author’s stories communicate this much. Estreich takes this a step further in relating such a concept to the irony of his father’s cancer diagnosis. Estreich’s father was an engineering consultant—a professional summoned to fix problems. Unfortunately, he was diagnosed with incurable lung cancer:

For years afterwards, I thought he was simply in shock at the news, and his empirical common sense had collided with an unimaginable fact. I think now I did not give him enough credit. He was an engineer; the unanticipated was routine. When I remember his stories about knotted power cords, unpredictable resonances, and blooms of spilled ink, I remember the engineer’s paradox he lived by: his belief in rational solutions was forever being tested by the misbehavior of the actual world. (p. 227)

After reflecting on the life of his father, and the surprising non-shock and what appeared as “giving up” to Estreich in terms of fighting for his chances for survival, Estreich realized that his father was prepared for this. His profession proved the maxim, *expect the unexpected*. Thus, it became clear to Estreich, and all the remaining three authors, ultimately, that control is an illusion, and the future cannot be rationally solved.

5. Temporal Insights Gained Through Disability

The meta-theme, *Temporal insights gained through disability*, reflects the over-arching idea described repeatedly by all four authors. Because they each must grapple with the linear temporal framework's pervasive tendency to exclude those with disabilities, because—to accept their child—they must come to accept their child's embeddedness in an alternative temporal framework, because each parent comes to value and see the benefit in the alternative ways of experiencing time and space beyond the precedent, and because they see the beauty in the many ways of being human and relating to time, they inevitability broadened the scope of time. Through their memoirs, Rapp, Brown, Gabbard and Estreich reveal that there are multiple ways in which one can relate to and experience time. Each of the children in study—Ronan, Walker, August and Laura—necessitate that their parents embark on a new relationship with time. As Rapp writes:

My time with Ronan was short and beautiful and shot through with light, laughter and, above all, a kind of love that stripped me to the bone. A magical world, yes, where there were no goals, no prizes to win, no outcomes to monitor. Ronan was given a terrible freedom from those expectations that was searing, brutal and, especially, *true*. (p.20)

It was Ronan who required his mother, Emily, to forcibly abandon the future; Ronan was promised no future, his Tay-Sachs disease granting him the guarantee of the present and that was all. This is counter to modern and dominant conceptions of time which have individuals employing moments in the present as catalysts for moments in the future (see the theme above, *Confronting the "precedent"*). Ronan—the most obvious example of the four children in study—influences his mother's relationship with time to an alternative relationship with time, one that represents and matches his alternative relationship to time. Ronan's being in the world is shaped differently, and as such, where Rapp stands in relationship to space and temporality is different too. No longer is she parenting according to the dominant temporality; she is parenting according to a different sense of how things unfold and happen in time. Although Brown, Gabbard and Estreich were privileged with more time than Rapp and Ronan, they also provide examples of a broadening relationship with time. As mentioned, time is typically thought of linearly, progressively, but, as each of the authors must confront, what might it mean to think more about time in the present? Walker, August and Laura live beyond the dominant linear framework of temporality because their disability excludes them from it. The dominant script of

control in the present over outcomes of the future is not necessarily true for them, due to the limitations caused by their physical and cognitive disabilities. Thus, their present is severed from the future in some ways, which preconditions their parent's future to be severed as well.

Together, all four children and their parents highlight the potentiality of time and the opening up of new relationships with time. Living linearly is not the only way one must conceive time; these authors and their children have shown us this. These findings, in short, show that disability is a resource for broadening our relationships with time. To conclude, I offer a quote by Gabbard, demonstrating another example of the alterity of time:

August's story is a circular book, one whose ending folds back around to the first page, where I begin it over again. The end is where I start. He and I travel together. We're a couple of rich men now. Despite knowing each mile of this journey, I embrace it. *Incipit vita nova*. (p.223)

Chapter 5: Discussion

To reorient the reader to the subject matter at hand, the purpose of my research was to investigate how some relate to time atypically. In the revelation of temporal difference, it was my hope to showcase the generativity of alternative ways of being in the world. To achieve this purpose, a qualitative memoir analysis was undertaken, employing four memoirs written by parents of children with diverse physical and intellectual disabilities as sources of data collection. The intent of this strategically structured project was to mount the positive implications of moving away from solely a future oriented, linear temporal orientation, pervasively emphasized in the North American, neoliberal culture.

To contribute to some existing discernments in disability studies literature that suggest we might perhaps seek to conserve disability rather than eliminate it, my specific research aims were:

- To understand how people relate to time both from a hegemonic perspective reflective of Western, neoliberal cultures as well atypical relationships with time.
- To disrupt the domination of linear time and point out the flaws in such a manifestation by exposing the existence of alternative relationships to time.
- To explore the idea that alternative relationships with time are rich with value and insight.

My overarching research question was: Are there insights to be gained from people who interact with time differently?

In this chapter, I begin by discussing my key findings and their linkages to critical scholarship relevant to temporality, parenting, childhood and disability. I then discuss the limitations and future directions of my research, as well as the implications of my findings for broadening the ways in which time is related to, interacted with and perceived. In particular, I discuss the possibilities for valuing alternative ways of being in the world, more generally. In the remainder of the chapter, I discuss the theoretical contributions of my research by providing new discernments into Garland-Thomson's (2012) "case for conserving disability."

1. Summary of Findings

Reading these memoirs was productive because each exposed how linear, future-oriented temporality has come to dominate the global north. Speaking broadly, due to the proliferation of neoliberal principles embedded within modernity's influence, childhood is instrumentalized as a mechanism for the production of ideal citizens. It is this particular discourse of linear temporality that presumes a standard and projected evolution from gestation through childhood in order to achieve the desired value in adulthood. Development, for instance, is considered the universal, ongoing accumulation of skills and abilities across time to a desired endpoint; it is this expansion and the prominence of future-building which has transpired into the emphasis on childhood. Evidently, in the modern world, the present moment (childhood) is used as an opportunity to shape the future (adulthood). Parental guides, education, therapy, medical advice and other resources for modern parenting are reflective of such an approach. The decisions we are making and the conclusions we draw when it comes to children are often implicated by the ways in which we see time and the ways in which society supposes we see time. The dominant temporality and framework are inherent in these efforts.

When the process of instrumentalization goes awry, when one is unable to match the ideal trajectory of progress in their childhood—or the standards of temporal linearity—curative time, the effort to reassert linear development, is employed to restore normalcy and assimilate difference. We do not think of it in terms of time, we simply think of it in terms of rehabilitation, for instance, desiring to get the individual back on the dominant temporality and framework. Implicit in such actions is an ideology that is unable to project value to a life where development is not tractable and the future not amenable. When one is unable to have a predictable future, or narrative of sorts, the psychological axiom of neoliberalism—principles which our society reflects—is unable to sustain its control of the future and its efforts to maintain stability. This subversion is not indicative of dominant axioms; thus, those who present as a barrier are problematized. Evidently, the strength and sustenance of linear time and its implicit ideologies has resulted in the narrowing of possibilities of ways of being. Thus, disability represents a problem with temporality as it is formulated in modernity. Yet, it also opens up resistive and transgressive potentials: disability problematizes the axioms. It has been discussed that when one is unable to live up to the developmental narrative and the dominant temporality, the axioms are

exclusionary and close down possibilities for being. However, by the same token, when the singularity is imposed and some are inevitably marginalized, possibilities for alternative ways of being are disclosed, and there is merit in that. The impetus of this study lies in revealing part of the discourse of the potential of disabled bodies and their alternative temporalities.

To contextualize and reflect upon the transgressive potential of disability, the analysis suggests that Emily Rapp, Ian Brown, Chris Gabbard and George Estreich all grapple with this pervasive temporal linearity in the raising of their children. Because each child has been diagnosed with a disability, whether physical or cognitive, their individual body and mind present a challenge to living linearly. Rapp's son, Ronan, for instance, has Tay-Sachs disease; he will not live longer than three years. Walker, Brown's son, has cardiofaciocutaneous syndrome, which prevents him from verbally communicating, affects his cognitive and executive function and requires him to wear restraints to prevent self-mutilation. August, Gabbard's son, was born with an impaired body as a result of unexpected medical error; he is both severely mentally and physically affected and experiences constant health complications. Lastly, Laura, Estreich's daughter, was born with an extra twenty-first chromosome—she has Down syndrome. Although Laura can physically perform and verbally communicate, her developmental age does not match her biological age. In this sense, all four parents must confront what I have called the temporal precedent (i.e., linear time, reflective of achievement, endpoint, landmarks, and so on). Although their experiences are unique and their children are different, findings showed that parents experienced a similar “trajectory” of sorts: first, they had to confront the linear temporal framework in that they realized it did not represent them. They had to learn that accepting their child resulted in a new relationship with time and space—one that they would not have experienced otherwise, without the presence of their child in their lives. This will be referred to as *prosaic time* (see Morson, 2013) reflective of the routine and everyday time. While this enlightenment of sorts progressed, they each came to realize the value in this alternative way of experiencing the world, one that allowed them to employ their imagination and creatively construct possibilities rather than constraints for themselves and their children. In employing imagination, they clamored for a new perspective on time, one that allows the mystery of the individual to be reclaimed. Together, as each parent comes to accept and value their child and their inherent opposition to the dominant rendering of time as something that employs the present as an opportunity to shape the future, their relationship with time itself changed.

Otherwise speaking, the extracts from each memoir suggest that the four parents included in study were influenced by their children to consider and experience an alternative temporality. Because the child could not match the temporal standards of their surrounding society, each parent had to forcibly abandon that hegemonic relationship to time and broaden their own.

In what follows, I situate my findings in the critical scholarship on disability, parenting, childhood and temporality.

2. Locating the Findings in Literature

2.1 The consequences of the dominant developmental framework

My findings reveal that widely circulating ableist discourses regarding normative childhood development are central to producing the exclusionary “linear life narrative” which modern parents are expected to follow. This idea resonates with a wealth of critical scholarship on childhood disability. In particular, the implied problem constituted as “abnormal” development when development is considered contextual, provisional and locally produced, as opposed to a unitary, universal and consistent process (O’Dell, Brownlow & Bertilsdotter-Rosqvist, 2017). O’Dell et al. (2017) suggest that the notion of development has become acclimatised as an assumed progression through time, representative of linearity, as one is to move in the direction towards a particular endpoint (e.g., children’s development as a biological process of advances in abilities through time). Later, the authors counter that such a proposition of a developmental trajectory establishing a naturalized link between the past, present and future is unhelpful to those who transgress the “biological” framework and the interwoven cultural priorities embedded within such a construction. My examination of parents grappling with temporal normality suggests similar claims: not everyone is able to move towards a specific endpoint—sometimes individuals move through time cyclically or degenerate quickly. Although it appears obvious that children grow to adulthood, this understanding of children increasing in proficiency through time flows out of Judeo-Christian theology and the historical advent of evolutionary thinking (O’Dell et al., 2017; Vandenberg, 1993; Rose, 1989). In saying this, my work falls in line with other authors such as Halberstam (2003), Stockton (2009) and Dyer (2017) who suggest that alternatives to heteronormative time exist, such as the employment of a queer theoretical perspective of development and temporality. Through this alternative framework, time and developmental trajectories are not based on historical and contemporary priorities of the

global north (e.g., desired outcomes of development, such as rationality and independence or a life course revolving around heterosexual reproduction), and in fact function to resist definitions of non-normativity as “an expression of immaturity or a lack of development” (p.152). My findings are consistent with the notion that development should be reconsidered as a flux and fluid move through time rather than a progressive and cumulative naturalized practice. The plurality of time, consisting of the plenitudes of ways in which individuals relate to and interact with time, is exposed when alternative temporalities are disclosed.

2.2 Rehabilitative time to reassert normative development

Further, prevailing assumptions of normative development embedded in developmental psychology and institutions reflective of the neoliberal hegemony shape understandings of disabled children as in need of remediation. Critical scholarship suggests that for disabled individuals, the future is framed in curative terms—only when one is rehabilitated, normalized and hopefully cured, can one contribute properly to society (Kafer, 2013; Cooper, 2020; Mollow, 2012). In examining how time is utilized in order to “correct” the body’s movement through space, Cooper (2020) and Kafer (2013) refer to “rehabilitative time” as an activity taken to normalize embodied relationships with space-time. Cooper (2020) specifically refers to the “rehabilitative chronotype”, which employs “time (and resources) to restore a child to the ‘correct’ occupation of space” (p.77). This chronotype is to be always set against the “developmentalist chronotype,” which expects the child to align their space and time normatively; consequently, when the temporal development of the child is misaligned with the developmentalist chronotype, it is conceptualized as a problem. What Cooper is suggesting is that the notion of time spent rehabilitating is time spent outside of time, as the efforts are put in place to get the child back on the dominant temporal framework. In this regard, Kafer (2013) examines how eugenic histories hold the position of “reproductive futurity” (p.30), which forms the foundation of the developmentalist chronotype. Kafer suggests that during the first half of the twentieth century, thousands of individuals identified as possessing some sort of “defect” were targeted by policy and professionals in order to “contain the alleged risks they posed to public health” (p.31). Implicit in such eugenic discourses is this idea that children serve as a notice of the future—the kind of children who are borne determine what the world will be. Thus, those who were diagnosed as ill, defective, deviant or disabled were positioned as “fundamentally

damaging to the fabric of the community,” particularly in regard to public health, governmental services, quality of life for the family, and so forth (Kafer, 2013, p. 31). In this sense, disabled people historically were situated as threats to futurity. Physiotherapy, or other reconstructive medicalized efforts, are contemporary examples of motivations to facilitate the “normal development” of the child’s body. Mollow (2012) uses the term “rehabilitative futurism” to describe the process of re-establishing the future through rehabilitative time. The findings of my research would seem to fit alongside assertions made later in their papers by both Cooper (2020) and Kafer (2013) regarding how treatments that are rehabilitative are not always of benefit to the child—from a bioethical standpoint, most medicalised treatments promote the ideology that normative development is the only progression through space to be desired. In this sense, rehabilitative time functions to promote development in a narrow, prescriptive way, predicated on the assumption that there is something deeply wrong with the individual who needs it.

2.3 The harmful messaging of linear temporality

Phelan, Wright and Gibson (2014) argue that the implicit and explicit messages about disability communicated via rehabilitated materials can often reinforce pervasive negative messages about disability that are internalized by children and their families (i.e., “fixing” the individual). Rapp challenges notions of rehabilitation in reference to her engagement with Ronan in Reiki acupuncture, as opposed to modern forms of life-expansion efforts:

Reiki energy doesn’t save people in the way we’ve come to understand it according to western medical practices. It simply helps the body do what it needs to do [...] No breaking free of the leg braces a la Forest Grump, no miraculous healing of a disease that in turn suggested an open landscape free of pain, a future that was fixed and without struggle. (p.143-145)

Despite the preoccupation with temporal normality from the perspective of rehabilitation, Rapp resisted the urge to employ traditional medical based therapies to overcome deficits to seek some form of normality. In line with flaws pointed out by Fisher and Goodley (2007), Rapp stopped looking to medical expertise for recovery and normality and instead allowed for a mobile, shifting and unfinished process of in-the-moment healing. As Cooper (2020) suggests, to resist the cultural forces outside of oneself, one must make protracted and difficult movements toward agency; in essence, parents have to challenge notions of rehabilitation. This is often difficult, however, as in her work on problematizing the transition for individuals with developmental

disabilities into adulthood, Hamdani (2016) found that parents often reproduce powerful medical discourses that constitute disability as a “problem” to be prevented and minimized. All the parents in her dissertation research pursued rehabilitative interventions to address their children’s disabilities and atypical developmental trajectories, demonstrating the power of Cooper’s (2020) “rehabilitative chronotype” set against the “developmentalist chronotype”. When developmental stories are internalized, temporalities become taken for granted.

2.4 The dual nature response of parents

My findings showed that conceptions of time are essential to the discourse around disability, particularly when the children are first diagnosed. Maternal studies scholars Fernandez and Robertson (2019) examine how disability seems to cause time to collapse in a novel way. For parents, following the diagnosis of disability, the future of their child is suddenly brought close to their vision, whilst at the same time, eluding their reach. Fernandez and Robertson (2019) contend that it is the mother who is confronted with visualisations of their child as an adult struggling; existing alongside this sentiment, however, is the feeling that the child’s imagined future is stolen. These contrasting feelings result in parents perceiving the future as something that is both present and unimaginable and directly opposes the experience of a parent of a non-disabled child, “who simply lives with the unexplored, generalised and distant notion of the assumed adulthood of their child” (p. 43). In her work on altered temporality in contemporary motherhood memoirs, Thomas (2018) argues that it is here, during diagnosis, that maternal time diverges from the everyday linear time of neoliberalism. Following these scholars, my research suggests that parents of disabled children experience both sorrow and lamentation for the dichotomous robbed and proximal future, whilst at the same time experiencing love and embrace for the individuality of their unique child. Landsman (1998) refers in this regard to “the dual nature” of parenting a disabled child, where mothers acknowledge both the emotionally painful, physically exhausting and time-consuming hard work that parenting entails, as well as the fact that they would never choose to give up their child or what they have learned in the experience. In her work on the existence of recurrent grief in mothers of children with intellectual disabilities, Brown (2016) refers to these conflicting feelings as the personal response to a dual loss of imagined reality for mother and child. However, Brown also recalls the ongoing process of meaning making typically leading to transcendent and transformative experiences or post-

traumatic growth with increased resilience. In this sense, grief experienced by the parent is adaptive, dynamic and circular and goes on throughout the life of one's child. Similar to the participants in this study, the initial grief response is child focused; however, "in gaining mastery over the practicalities, grief moves over into the family and society" (p.119). It is the dreams and the imagined reality based on societal expectations that needs to be let go—to do this, parents must engage in a process of questioning and making sense of the loss whilst constructing a new reality for the child and themselves around the disability.

2.5 Parents coming to accept their children

In contrast to the abundance of patronizing²³ literature on parental coping strategies following the birth of a disabled child (see Yirmiya & Shaked, 2005; Powers, Sowers & Singer, 2006; Hayes & Watson, 2012), many of the findings parallel descriptions found in multiple works by maternal studies scholar, Gail Landsman. To begin, in her 2003 publication on asking how mothers of disabled children define their own and their child's identities, Landsman found that mothers often stand "at the center of a great paradox, saying to their child both: 'I love you as you are' and 'I would do anything to change you'" (p.1949). Throughout her work, she speaks of the narratives of hope (i.e., where the commitment lies to pursue a life without disability through rehabilitative or activism efforts in hopes that the child gets back on track with the folds of normalcy) and narratives of acceptance. Despite the common desire for parents to assist the child in the curing of their disability, whatever it may be, some of the participants in Landsman's (2003) work experienced a fading of that yearning. These parents appeared to believe in their child's full personhood without any measures of progress or any indications of overcoming the disability, similar to the parents in this study. These parents refused to compare their child to the norm, or the standard model of developmental maturation. As Landsman (2003) writes, "In part mothers who come to abandon [developmental delay] do so out of their belief in the impossibility of comparison, their understanding of the uniqueness of each child" (p.1957). The mothers in Landsman's (2003) study, like the four parents in the current study, came to value the interrelationship of their child's disability and their child's identity. In the simplest terms, the parents in both studies came to see their child's personhood as inseparable with their disability.

²³ Patronizing due to the harmful messages communicated about disability (i.e., *the disabled child will have a damaging effect on families so here is how to cope...*).

In another of Landsman's works, published in 1998, mothers were interviewed with the intent to explore mothers' own perceptions regarding the birth, the diagnosis and the experiences of living with their child's disability. Landsman (1998) found that "foregrounded in the stories of mothers whose children have already been diagnosed for some time are redefinitions of quality itself, reflections on what constitutes or should constitute perfection in a child" (p. 87). Interestingly enough, a common theme across Landsman's and my work is how parents' identity is impacted by a new awareness of what matters in life. In coming to learn through nurturing that their disabled child is valuable and fully human, parents appear to come to redefine their own parenthood. Landsman expands this idea in her 1999 publication, "Does God give special kids to special parents?" In this work, parents speak of parenting a child with a disability as transformative: "in this model, normal women are transformed into special mothers by special children" (p. 145). The transformation does not come as a result of some innate attribution buried deep within, according to these participants, but rather is acquired through the child as a catalyst. In this sense, similar to the sentiments shared by Rapp, Brown, Gabbard and Estreich, the child comes to be conceptualized as the giver of the gift. In reinscribing their child's personhood this way, counter to dominant discourses on the tragedy of disability, "a mother of a child with disabilities raises the value of her child beyond that of the 'perfect' child she had once expected to acquire" (p. 148). In this sense, the child as the giver of gift challenges old discourses of disabled children by offering a more positive account of disability where the child functions as a gift of insight, a gift of knowledge and as a catalyst to redefining oneself.

2.6 Play is just play

Mitchell and Lashewicz (2018) conducted similar research on the ways parents embrace their children but did so from the perspective of fathers. This methodological choice parallels my research, as three of the four participants brought forward were men. In this work, Mitchell and Lashewicz (2018) researched the experiences of fathers of children with autism spectrum disorder in the context of father-child play interactions. A significant finding in line with the theme of *Acceptance* generated in this research pertains to how fathers positively interpreted their child's play as "repetitive" or "quirky," without attempting to mould or change it. In this sense, they accepted their children's natural proclivities, distinct as they may be from their own. In doing such a thing, the fathers' resisted dominant storylines of autistic children's play as

deficient. Like Gabbard, these fathers understand play as just play—it is not erased in the achievement of something that comes after it. The children are doing what they do, and the parents make sense of it by searching for meaning that accords with their child’s unique way of doing it. This is in stark contrast to evaluative play as well as the instrumentalization of play in rehabilitative and therapeutic contexts (see McLaughlin et al., 2008); they are just letting them be and allowing their children’s play to be an act of pure self presentation. The fathers resisted employing play as a tool to remedy, cure or catch up to normative definitions of development. In this sense, the fathers actively resisted temporal linearity and its pervasive underlying of normative development; doing so oriented them to an alternative orientation to time and space, where play is considered something that “is what it is”. Perhaps that is what Landsman (2003; 1998; 1999) refers to in her assertion of transformation on behalf of the parent: in accepting their child and their unique way of being, parents are granted insights they otherwise would not have achieved without the presence of their child in their lives (more on this in the implications to follow).

2.7 An altered temporality

In the theme, *imagining a life together*, I stress how Rapp, Brown, Gabbard and Estreich draw attention to the ways in which certain aspects of a child’s uniqueness lead parents to adopt alternative and constructive frameworks of meaning. In her 2015 work analyzing maternal temporality, Robertson asserts that mothers of disabled children can become “disabled” themselves through continued struggles to situate themselves within “chrononormativity” while attending to their children’s demands. In this sense, Robertson (2015) frames these mothers as challengers to “chrononormativity,” defined as “the use of time to organize human bodies into maximum productivity through the use of clocks, schedules, calendars and time zones which inculcate particular temporal experiences and privilege powerful groups” (p.4). Because the four parents I brought forward exhibited a failure to fit within normative time and space in being in relation to their child, they themselves presented a challenge to chrononormativity. In line with Robertson (2015), there is generative potential to this altered state of temporality. As she states, “[the mother] may, by virtue of their non-normative embodiment and experiences, contribute specific ways of knowing the world” (p.7). Simply put, their insights propose an alternative temporality, a temporality more specifically oriented towards the here and now.

On the basis of an altered state of temporality, there are alternative narratives that parents can take upon themselves. For example, Fisher and Goodley (2007) present three recurring, inter-linked and, at times, contradictory narratives offered within the accounts of twenty-five parents of babies and young children with special needs. The first is titled “the linear narrative” and it bears great resemblance to previously outlined binary thinking regarding normal versus abnormal development and trajectories. There were times in each of the four memoirs when the parents would construct their child’s disability as pathological and, particularly at diagnosis, wish for their child to be different. One would be remiss to exclude the fact that the narratives are not mutually exclusive and can interweave in a fashion that defies any attempt toward a rigid categorisation. In saying this, parents in my study embraced one or two of the other frameworks of meaning as well, described as follows. The second narrative that Fisher and Goodley describe is titled “narratives of challenge”, which refers to parents actively resisting conventional notions of individualized pathology and instead locating disability in the context of sociality. This narrative most aligns with “social model thinking” developed by disability activist organizations (see Murray & Penman, 1996; Murray, 2003). The parents in this study, however, did not typically take upon this narrative—if anything, Gabbard particularly resisted the narrative of challenge, as it relies upon an individualistic ideal of independence. He writes:

I began to detect a disconnect between the goals of the disability rights movement and the needs of our son. The movement promoted the emancipatory project of independence and self-determination for disabled people. The individuals spearheading this social justice campaign were primarily people with able minds living with mobility or sensory impairments. The possibility of living and working independently in the community would indeed be realizable of them, if only society would lower its barriers to access [...] But this dream would never be feasible for August. [...] He would always need someone to speak for him. [...] As a disabled person, August occupied an uneasy place in the movement. In fact, he was an outlier, a marginalized figure even among the disabled. Because he couldn’t keep up with their drive for independent living, and because he could not speak for himself, they had to leave him behind. (p. 106-107)

Thus, others, similar to Gabbard whose children are unlikely to relate to the world independently, must devise additional stories that are less reliant on a unified plot of independence towards future goals, premised on a linear temporality and linear narrative. Enter Fisher and Goodley’s (2007) third node: “the philosophy of the present”—this is the narrative that pertains most relevantly to the accounts considered in my research. Fisher and Goodley (2007) borrow the expression first articulated by Davies and Ezzy, who deem it as a liberation

from the future through a commitment to the present. According to Fisher and Goodley (2007), those who register as *philosophers of the present* “interpret uncertainty as an opportunity to focus on the quality of life in the present” (p. 74). The four authors here shared their experiences in realizing that the future is not always amenable to control; as such, they were continually open to possibilities. Fisher and Goodley (2007) claim that in employing a philosophy of the present, individuals must view their own life as relational and ongoing, similar to a book that can be opened up at any point. In revisiting the aforementioned idea of disability as a site of potential transgression, certain aspects of a child’s difference enable alternative nodes of understanding which may challenge hegemonic values. The psychological axioms of the neoliberal desire for individuals to develop as per a standardized developmental timeframe are questioned when one is unable to live up to that developmental narrative and its associated temporality, and as a result greater possibilities for being are exposed. Thus, this research fits well with Fisher and Goodley’s (2007) theme, “the philosophy of the present”, as each of the four parents revealed how, alongside their children, they transcended the dominant temporality into a temporality more oriented towards the present. As opposed to thinking about time as per the dominant precedent, parents were exposed to the idea of thinking more about the here and now.

2.8 Prosaic time

With respect to the “philosophy of the present”, it is important to elaborate by way of the notion of openness and prosaic time. Morson (2013) contends that “Time is open, the present moment makes a difference, and whatever does happen, something else could have” (p. 1). That is to say, outcomes are not inevitable, and consequently, determinism (e.g., only one thing happened at a given moment) is not possible. Morson (2013) introduces his audience to the idea of open time, contending that the world is filled with an abundance of possibilities; in his words: “I believe deeply that at any given moment, more than one subsequent moment is possible” (p. 2). What is interesting about his thoughts is his commitment to the existence of more possibilities than actualities. In reference to the dominant temporal framework which instrumentalizes the present in favour of a desired endpoint in the future, openness states that one can not in principle predict the future moment, despite efforts to rehabilitate and “cure” disability. As opposed to the corroboration of the linear temporal narrative, my findings explicate an alternative vision of the world in open time. For the children of Rapp, Brown, Gabbard and Estreich, every moment is a

present moment; as expressed by their parents, they do not have a concrete plan for development necessarily—it is often solely what they do in the moment that matters; Morson (2013) refers to this as *prosaic*. *Prosaics* orients us to events that are the most ordinary and everyday—events that are so commonplace, they are often missed. With reference to temporality, then, *prosaic time* is the time of the everyday; it is not a time that is constrained by developmental landmarks or skill acquisition for the betterment of tomorrow, but rather events that are routine, familiar and oftentimes, escape our notice (Morson, 2013). In saying this, a *prosaic temporality* captures the immediacy and the here-and-now qualities of an interaction. With respect to Ronan, everything was experienced in the present—immediate touch, taste, sight and sound with no cognitive recall. He was only able to receive direct experience that ended as quickly as it began. Moreover, in Brown, Gabbard and Estreich’s accounts, it was the ordinary days and times together that were privileged, as opposed to the grander moments of their childrens’ lives. The parents did not measure the value of their children in terms of overcoming (i.e., representative of the linear temporality where some version of an endpoint is reached), but instead valued each of their children for who they were/who they are in the here and now. Their lives were premised on a different type of temporality—a *prosaic temporality*. In short, these children influenced their parents into an alternative relationship to time—as Morson (2013) refers to it, a *presentness*. Although, as discussed previously, parents are not rigidly oriented in one temporality or another (Fisher & Goodley, 2007), the presence of their child’s disability as well as their alternative temporality functioned as a catalyst for the exposure of possibilities.

2.9 Outside the constraints of the dominant temporality

When these parents demand space in the world for their children, they function to dismantle the single story of disability, premised on a linear, progressive temporality which situates disability as tragedy. In her work, “Going ‘off grid’: A mother’s account of refusing disability”, Davies (2017) provides a critical account of a woman negotiating possibilities for her son by refusing the label of “disability”. In particular, the woman Davies writes about refuses the disablement of disability—by disablement, one is referring to the misrecognition of a person, their abilities, and the consequences of a label. Although none of the parents in my study went so far as to refuse the label of disability for their child, Davies (2017) unintentionally displays the advocacy on behalf of the parents to speak for the benefit of their child. Rapp, Brown, Gabbard

and Estreich advocate for the individuality of their children against the tragic narrative of disability, thereby aligning themselves with Davies' (2018) work.

Later, Davies (2017) provides a practical example of how the mother of this son writes to her family doctor with the intent to refuse the doctor's recommendation to make an appointment for her son with a psychiatrist. An excerpt of the letter follows:

I know that you are well intentioned and act in what you believe to be XXX's best interests, but I don't think that you understand what it is that disables XXXX. Within our family and our various communities, XXXX thrives and currently he is both happy and healthy. You seem to think though that because he is neither employed for money nor on some form of income support, that his life is restricted and that he is disabled. I disagree. XXXX is young and still working out for himself how he wants to live his life. I intend to support him as he works through his options and considers various possibilities. I honestly do not believe he is either unwell or disabled as he currently lives his life. (Davies, 2017, p.76)

By not arranging the psychiatric appointment recommended for her son by the family doctor, the mother is advocating for her son in the here-and-now. The use of the words and phrases, "currently", "still working out for himself", "works through his options", and "considers various possibilities" indicate that, similar to the findings revealed in this study, parents can advocate and demand space for their child in the moment. In this sense, the parent in Davies' (2017) work, alongside the parents in this study, reclaims the mystery of their child by reaffirming human possibility outside of the constraints of the dominant temporality.

2.10 Ethical decision making

Recall Estreich's assertion that, "For those who believe Down syndrome leads inevitably to misery, prenatal diagnosis provides the essential knowledge, the fact that misery can be averted" (p.190). Estreich's contention aligns with recent literature by Sandel (2007), which posits that the enhancement of reproductive choices offered to prospective parents fosters "a kind of hyper agency—a Promethean aspiration to remake nature, including human nature, to serve our purposes and satisfy our desires" (p. 54). While this genetic knowledge can foster opportunities for increased decision making, it is often employed with the intent to selectively reproduce (as Estreich states, "'Misery' can be averted" [p. 190]). Sandel (2007) argues that genetic selection should give rise to moral concerns, particularly with respect to the fact that one is granted the ability to decide whether or not to parent a child with characteristics defined by clinicians and

policy makers to be detrimental. To bring time into this, is the child rendered undesirable because they can not be valued in terms of what they will become? Soniewicka (2015) takes this idea and presents three ethical arguments with respect to genetic selection and disability. The first pertains to utilitarianism, which rests upon “the quality of life” and “costs and benefits analysis” (see Kymlicka, 2002); the second is procreative beneficence, which poses questions such as “what is the best outcome and for whom?” (see Savulescu, 2008); and the third is the rights-based approach, which invokes the rights and interests of future people (see Reiman, 2007), and advocates that parental decisions should be governed by universal, purely rational ideas. Simply put, each ethical argument is concerned with outcomes and future progeny. Later in Soniewicka’s (2015) work, she discusses a recognition-based approach to prenatal diagnosis and reproductive choices, which details the owing of equal respect to every human being, affirming the different expressions of the individual or collective identities. From this perspective, claiming that disabled children should not be born due to limitations in social welfare and supposed anxieties regarding quality of life reduces persons to their genetic characteristics and withholds recognition of human dignity. Soniewicka (2015) deems these misinterpretations as evidence of failures of imagination. When the recognition of significance of somebody’s life is rejected, imagination has failed. As Soniewicka (2015) states, “We have to assume that the perspectives of disabled people are worthy of recognition and care. We are *not allowed to assume that a society would be better off if they were never born*” (p.562). Underlying Soniewicka’s (2015) assertions and this research is advocacy for disabled individuals. The parents in this study employed a recognition-based approach—not necessarily in prenatal genetic decision making as formulated by Soniewicka—but in the raising and advocating for their child for their child and their right to a future in this world, a future unburdened by assumptions of what that future may look like.

2.11 Troubling futures

In line with discussions on prenatal diagnosis and genetic decision making, typically motivated by assumptions of fear of difference as cited by Soniewicka (2015), the findings of this research point to a need for troubling assumed futures of disability. Toward this end, scholarship by Gibson, King, Kingsnorth and McKeever (2014), as well as Hamdani, Mistry and Gibson (2015) seeks to identify discursive assumptions underpinning disabled youth transitions

to adult services and adult life. The intent of this work is to examine how traditional stage-based theories of human development seemingly drive funding and service models. Gibson et al. (2014) argue that “age is an arbitrary and inappropriate criterion for discharging and displacing profoundly impaired individuals from pediatric to adult institutional long-term care settings” (p.5). They advocate for a re-examination with considerations of best interests of individuals and families, intended to recognize their deserving of a good life in whatever forms it may take (i.e., narratives that see development in alternative ways). Hamdani et al. (2015) take this idea of meeting the individual needs of the person in their critical exploration of best practices for youth with Duchenne muscular dystrophy transitioning into adulthood. Their research shows that “dominant principles of normal development pervaded the four transitions best practice documents reviewed” whilst, at the same time, “the uncertainty of living with DMD was manifested in practices such as the deferment of the pursuit of adult milestones, and philosophies oriented to living well in the present” (p. 1149). That is a particular temporality. These dichotomous renderings of the transition documents and the interests of the individual clashed in the sense that the developmentalism embedded within the transition documents inadvertently worked to deepen the exclusion of youth who cannot easily achieve adult milestones due to their escalating loss of function. In this sense, Hamdani and colleagues (2015) advocated for “understanding youth as a social and generational category in its own right, with its own expectations and possibilities, rather than being understood as ‘un-adult’ or transitional, [as it] might promote development of interventions focused on maximizing well-being in the present” (p.1150). In sum, the accounts expressed by the parents in study in conjunction with the work of Gibson et al. (2014) and Hamdani et al. (2015) suggest that there is a need to trouble the assumed outcomes of development and query the notion of successful transitions into adulthood. To do this, we must broaden the measure of success in futurity, by expanding the possibilities for being rather than falling upon contrived outcomes.

3. Limitations and Future Directions

The study is limited because of the research scope and design. To answer such a broad question as is, “Are there insights to be gained from people who interact with time differently?” likely requires more than an in-depth rendering of four memoirs. Nonetheless, the themes and concepts presented in this analysis lays groundwork for future research that is in line with

priorities expressed by parents of disabled children; namely, research that seeks to leverage and bring into view more conscious understandings of temporality for clinicians, educators and the general public.

It is of note that the data set was comprised of published memoirs that have endured editing processes with marketing and promotional objectives in mind. While writing the memoirs, the authors must have made decisions about which parts of their experience would end up in their writing. So, while studying the parenting memoirs allowed me to try to capture the truth in what they are saying and shed light on a particular subject (i.e., their experience of time in raising a disabled child), one cannot claim that my work covers all the relevant facets of parenting. In addition, as these data were engendered from extant texts as opposed to structured conversations and interviews, there was no occasion for probing questions or conventional dialogue.²⁴ Moreover, even though it was the intention through philosophical hermeneutics to conceptualize the memoir as a source of cognitive truth and value (rather than generalizing experiences), it is important to acknowledge that the parenting memoirs studied were written by white, heterosexual professionals (one female and three males). This uniform grouping of participants has implications in terms of how perceptible the stories are but (perhaps) more notably, this is characteristic of the underrepresentation of diverse cultures, ethnic backgrounds, and sexual orientation in research. Increased scholarly attention from these diverse perspectives would produce valuable and deeper insight into whether and how culture, socioeconomic status and sexual orientation influence the daily experiences of those parenting children with severe disabilities. One must also mention that this research often utilized the gender-neutral term “parent” when evaluating scholarly literature; according to Read (2000) the term “parent” tends to obscure the fact that it is overwhelmingly, although not always, *mothers* who are the primary carers of children, and this is more the case when the children are disabled.

These limitations present opportunities for further inquiry. For example, my study focused on parents’ perspectives on their experiences of atypical temporality, which shed light on the alternative ways of relating to time, as well as alternative ways of being in the world more

²⁴ Although from a philosophical hermeneutical perspective, there was dialogue. There is a back and forth with the text—you develop an understanding that is subject to play as you continue to read. You approach the text as the other with a voice: the text starts to question your initial assumptions and challenge you. The insight comes through the back and forth. As Nielsen (2016) asserts, dialogue comes between you and the artform which changes you as you are open to it.

generally. Future research can examine the perspectives of young disabled individuals themselves grappling with linear temporality, as well as educators, psychologists and policymakers, to gain a deeper understanding of how linear time dominates and how alternative relationships to time are manifested in educative contexts and therapeutic contexts. This study does not generate the sort of evidence required for changing practice protocols in medicalized contexts, education and therapy; however, it does offer clinicians and educators a fresh take on how alternative temporalities are experienced by at least a few parents and children, thereby expressing the plurality of time.

4. Implications of Findings

My findings have implications for leveraging the generative potential of the existence of alternative temporalities. As I have shown, there is not only one way of relating to and interacting with time in the world, despite the pervasiveness of linearity. Questioning what lies beyond the linear temporal framework is a major implication of this work. Doing such a thing may result in a shifting of temporal priorities and perhaps recognition of the benefit of alternative ways of being in the world: simply stated, there are other ways of relating to time that do not privilege the future. These implications go beyond disability: they are relevant to development, education, play, dialogue and the status and integrity of the present moment. As a point of clarification, this work does not suggest that temporally orienting oneself to the future be abandoned or avoided in daily practice. Rather, one is prompted to question what it might mean to loosen one's grip on control over the future.

Four accounts of parents were approached with the intent to garner experiences of what it means to parent a child with atypical embodiments and alternative temporalities. Each account exposed the influence of the child supposing their parent into an alternative temporality. Because these parents were no longer able to invest in a tractable future with their kin, they were no longer in possession of a predictable narrative of the future. Thus, each came to define their interpersonal relationship with the child in the lived moment. In this sense, parents were faced with the task of both appropriating and challenging their own personal temporal logic. Of course, as dictated by each of the four parents, such a temporal reorientation produced conflicting feelings of both heartache and bliss, but also enlightenment and personal betterment of sorts, which would not necessarily be achieved if they were able to live normatively. In what follows, I

discuss three potential avenues for reorienting ourselves from the monopolization of linearity, including adopting openness, being with one another, and embracing disability. This section functions to address implications for all, which is what the aforementioned disability-as-resource notion implies.

4.1 Adopting openness

The multiplicity of temporality exposed in this work illuminates the reader to the existence of possibilities for relating to and interacting with time. Through this research, narratives were provided as to how disability can direct one's attention to the often-unamenable future. As well, this work sought to expose how disability can function as a transgression to the dominant developmental narrative and its inherent linear temporality, thereby prompting the existence of possibilities for alternative relationships to time to flourish. This work casts the openness to possibilities (or *what could be*) as an implication of study. Determinism, loosely defined by Morson (2013) as the supposition that only one thing can happen at any given moment, is confronted when time is considered as open, the present is considered as its own entity and an acknowledgement of "whatever does happen something else could have" occurs. This research argues that it is in the embodiment of this registry—accepting uncertainty about the future—that the opportunity to focus on the quality of life in the present is supported. When an individual takes it upon themselves to be open, they can experience a lack of restriction to the abundance of possibilities the world consists of; in this sense, this rendering of the world as open may explicate an alternative vision of the world in open time. It is this particular embodiment that reaffirms human possibility.

Although temporality is an ever-present feature of our reality, it is often buried and inconspicuous. This work has intended to demonstrate that linearity is pervasive, and perhaps precisely because of this pervasiveness it is often difficult to pick out the functions of such a marginalizing ideology. In relation to implications, this work does not recommend disrupting linear temporality by negating the future completely, but rather, by safeguarding and seizing the moment, allowing those moments to be prosaic in-the-moment moments, not guided by something down the road. In doing this, the change may result in some consequences in the future (i.e., reimagining how we think about the institutions of childhood outside of the dominant orientation to time). In what follows, I will revisit the dominant caricature of development in

neoliberal culture, education and play, highlighted in Chapter 2 as mechanisms of hegemonic temporality, and will explicate how an adoption of openness can be considered within these three contexts.

In relation to development, the implications of an adoption to openness can be considered in particular. With regards to the “developmentalist chronotype” and the “rehabilitative chronotype” expressed by Cooper (2020), findings from this analysis highlight the need for health and rehabilitation professionals to be aware of the effects of implicit assumptions that constrain the futures of people with disabilities (or atemporal embodiments). When young disabled children are pathologized and compared to normative standards throughout their lives, an inadvertent perpetuation of social marginalization of their unique bodies is cast (i.e., because they may be unable to “match up” to the independent ideal of eating on their own by age three, their embodiment is shaped as lesser). In short, the temporality inherent in dominant developmental narratives oftentimes functions to constrain people’s futures. Not only do parents and the individuals themselves internalize expectations of what they should be, so does the wider world. Consequently, when children are held against these standards of developing as close to normal as possible, socially, politically and medically, deviations from normality are deemed “defective”. These findings have implications for considering how ideas about the “disabled child” and their tragic futures are perpetuated. With regards to transitioning to adulthood, it is unfair how subtle and pervasive “normal” roles are promoted as the only path to later life. According to Hamdani (2016), this must be actively countered through ongoing dialogue, values clarification and exposure to alternative ideas. Multiple options for living a good life should be supported, including living a good life in the present. We are freed up by the existence of different narratives—we should not be bound to a single one. Having more narratives at our disposal premised on different conceptions of time might liberate us all, rather than perpetuating a singularity that “this is what we should be doing at this age”, for example.

To respond to the question of what it might mean to rethink education more in terms of openness and the present moment, one may look to the clues inherent in improvisation—actions that are premised on a different sense of temporality. In their work on improvisation in the mathematics classroom, Andrea Young (2013) posits that tenets of improvisation can be applied in the classroom to foster open and engaging mathematical lessons. In a previous chapter of this

work, public education in neoliberal society was taken as a pre-engineered structure that is orderly, organized and goal (future) oriented—not a place of student-centered improvisation and self-direction in real time. Alternatively, Young (2013) demonstrates that improvisation—referred to as actions that are made up on the spot²⁵—can help students to learn to take risks in the classroom, fosters a sense of joy and excitement, and can demonstrate that fear and uncertainty can be embraced. What is most salient here, however, is the temporality on which improvisation is premised. It is not governed by some sense of the endpoint—one is actually liberated from the expectations when engaging in the practice. According to Verducci (2016), improvisation functions to get individuals engaged in the subject matter: “The improviser [must] become alive to the present as it unfolds” (p. 501). The temporality inherent in Verducci’s assertion of “becoming alive to the present” and subject matter is very different from the temporality inherent in current rigid standards of achievement which currently characterize typical educative settings (see Chapter 2). Improvisation requires one to release their need to be right or logical or to follow the rules; in this sense “improvisers can be open to changing and being changed by the actions on stage” (p.469). Taken together, my findings suggest, alongside Young’s (2013), that an openness to possibilities can actually foster growth. If educators could apply improv—which is inherently applying principles of openness—techniques to create simulating classroom environments, perhaps other pervasive and subtle lessons can be communicated to the students, such as abandonment of control and increased democracy. Exposure to alternative ideas in education may function as one of the keys to countering the ubiquity of rigid and fast-paced, planned development (reflective of linear temporality). In short, improv can be one way students are oriented to alternative temporalities, in that they may be taught to open themselves up to the moment and what it affords them.

With regards to play, an adoption of openness may be as simple as rescuing play from able-bodiedness and instrumentalization (Claughton, 2015). Although play, from a hermeneutical perspective, is conceptualized as “movement without purpose of endpoint” (Laing, 2012, p.3), earlier, in Chapter 2, we saw that the intrinsic value of play has been obscured by adults seeking to focus on its instrumental value (Goodley & Runswick-Cole, 2010). Several scholars have advocated for the emancipation of play from the domains of assessment and intervention for

²⁵ It is important to mention that good improv sustains a thread of sorts—it is not simply one distinct moment from another (see Verducci, 2016).

disabled children in particular (e.g., Claughton, 2015; Goodley & Runswick-Cole, 2010). Findings of this study are in line with such conceptions, as the instrumentalization of play threatens spontaneity and alternative forms of possibility and potentiality, aside from the potential for fostering unidirectional development towards a desired endpoint. Goodley and Runswick-Cole (2010) advocate that “severing the link between play and development, play and normality, play and normalisation, will we hope allow disabled children and their families repossess play” (p.510). This work simply adds to that stipulation by encouraging play to happen to increase possibilities for a cultivation of pleasure in the present moment. Play should be considered one characteristic of childhood that is not affected by linear time; when defined as “spontaneous” and “without endpoint” (Laing, 2012), it is almost as if play is suspended from time in some ways (i.e., an alternative temporality). Play should just be play—it should not be erased in the achievement of something that comes after it.

4.2 Being with one another

To introduce this next section, I offer an assertion made by Sandel (2007):

In a social world that prizes mastery and control, parenthood is a school for humility. That we care deeply about our children and yet cannot choose the kind we want teaches parents to be open to the unbidden. Such openness is a disposition worth affirming, not only within families but in the wider world as well. It invites us to abide the unexpected, to live with dissonance, to rein in the impulse to control. (p.60)

Sandel (2007) advocates that children are to be accepted as gifts, “not as objects of our design or products of our will or instruments of our ambitions” (p.55). Sandel’s work closely aligns with one of the main implications I propose pertaining to openness and leveraging alternative temporalities. Currently in society, and ever-increasing with the slow manifestation of normalizing genetic selection, the world strives to master the mystery of gestation, birth, childhood and development. Individuals, often expressed most clearly by parents themselves, are getting away with what Sandel (2007) refers to as transforming love (i.e., promoting accomplishments from their children) as opposed to accepting love (i.e., affirming the being of the child). To this end, findings from this analysis recommend a careful balancing of both types of love through an embodiment of acceptance to whatever qualities the child may express (accepting love), as well as a commitment to the cultivation of their own unique talents and gifts

(transforming love). Both require openness as well as a present orientation to the child in the now, not what the child *could have been* nor what the child *could be*.

When one approaches the child in the now and as they are, real implications for how we might engage children and one another, more generally, become illuminated. In short, changing our conception of time has implications for our being in the world with others. When we approach one another in the here and now, premised on this alternative temporality—whether open or prosaic—the other should be perceived as having a fully valid voice. When the other is considered as having a fully valid voice, their capacity for challenging another’s perspective on the world is enhanced. Yet, in the linear temporal framework, a sense of superiority underwrites our choices, behaviors and actions. Recall, “the ideology of adulthood” (Kizel, 2016) and its roots in linearity; the “ideology of adulthood” is reflective of a narrative (and a temporality) that is premised on a perception of childhood as a stage of immaturity, dependence and incompleteness and adulthood as its opposite: the end of incapacity (Kennedy, 2006). In this sense, in the normative encounter between adult and child, informed by the dominant, progressive temporality, adults often discount the cognitive value and perspectives of children. This is because a child is seen as a “person of this type” (i.e., age). When age and markers of childhood, adulthood and so on interfere with the ways in which we interact with one another and position ourselves in the world, the palpable consequences of temporality become exposed. However, in going back to the alternative temporality, premised on the here-and-now, there is potential for leveraging the competency of another—regardless of age, achievement or other psychological barrier that functions to seep away the importance of what another is saying. For example, in their work on progressing children’s participation, Graham and Fitzgerald (2010) advocate for dialogic encounters grounded in respect and recognition of the other; with respect to this study, the authors are suggesting a dialogue premised on an alternative temporality. This encounter is ethical in a sense because “it implies [adult’s] conversations with [children] begin from a standpoint of respect for their views, perspectives and assumptions” (Graham & Fitzgerald, 2010, p. 9). The adult is open to the new understandings and insights that can be generated and recognize that the other has the potential to engender them—the conversation is taken seriously, and the moment is seized between conversational partners.

It is not to say that communication is necessarily required in order to be with one another in this temporality. Rather, it is important to acknowledge the openness that is required to approach one another in order to garner the benefits that they can bring into one's life (premised on an alternative temporality). Take for instance, Brown, who approaches his son Walker as a source of insight into the world.

Walker is a lens [...] through which to see the world more sharply. Walker makes me see the ornament for what it is—better still, for what it could be, for what it might be. *Look here, Pa, he says, see what you missed. All you have to do is slow down. Let me show you how.* (p.242-243)

Brown is seeing a lesson in Walker's intention; he is dialoguing with his son in a sense by listening to him and allowing Walker's perspective to say something about what it means to be in the world. In short, Brown is opening himself up to his son's way of being in the world in a way that challenges his own conception of it. An alternative temporality affords this type of dialogue. Again, the implication reflects the idea that in an alternative temporality, we do not see the other as an incomplete person, but rather as a fully capable being that can inform, challenge and affect our understanding of the world. In appreciating someone in the here and now, we are embedding ourselves in an alternative temporality.

4.3 Embracing disability

The exposure of alternative temporalities may sensitize readers with a counterpoint to the ways in which one is to think about time and even disability, more generally. Disability is often cast as a burden to both family and society. However, if disability is alternatively embraced as a dimension of difference rather than a problem to be fixed then alternative and constructive frameworks of meaning can be achieved. Recall Brown (2016) who made note of the ongoing process of meaning making on behalf of mothers leading to transcendent and transformative experiences. Or Landman's (2003) work with parents who came to believe in their child's full personhood without any measures of progress or any indications of overcoming the disability. Findings from this analysis sought to explore disability in a way that opens up these ideas. In doing such a thing, disability is cast as something that is to be embraced, and therefore, valuable.

According to Soniewicka (2015), “one’s own identity depends to a certain degree on its *recognition*, the absence of the recognition or misrecognition by the others” (p. 562). We depend on one another to understand ourselves—true identity is not inwardly generated. So, when, in the context of genetic selection, disabled children are deemed undesirable, there is a withholding of recognition to the existing body of disabled people. “It is based on the reductionist view of human identity, which reduces persons to their genetic characteristics constituting the common mistake of treating *a part as a whole*” (Soniewicka, 2015, p.562). In reference to genetic selection, simple metaphor asserted by Soniewicka (2015) follows: just as one cannot tell what a film is about by placing a DVD beneath a microscope, neither could a person be understood by the analysis of the genome. Thus, findings of this work recommend conscious recognition of the significance of somebody’s life. Similar to the parents brought to the forefront in this work, who were primary researchers in discovering the value in each of their children’s lives, we as a society have to assume that the perspectives of disabled people are worthy of recognition and care. If not, according to Alasdair MacIntyre (2007), we are withholding recognition, which is one of the worst forms of oppression.

In this sense, this research may provide testimony for many of the significant arguments produced in Garland-Thomson’s (2012) account of the importance of conserving disability. There are temporal insights inherent and accessible through disability; in this work, this has come to mean that something lies beyond the linear temporal framework and that there is potential in this alterity. When each of the four parents in the study—Rapp, Brown, Gabbard and Estreich—came into contact with their child and their atemporal embodiments, they were exposed to the broadening of how one can approach time and relate to it. In this sense, findings recommend that disability be cast as a valuable, existential resource, implicating time. It rescripts our temporal practices and understandings (Garland-Thomson, 2012) and it breaks the notion of mapped linear development from dependent child to independent and autonomous adult (Robertson, 2015). Rendering the future as not controlled by the past and present allows individuals to live in the present without the shadow of the future—or at least, be at peace with possibilities over actualities.

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