

“A disconnect between what she wanted to do and her ability to act upon it”: Complexities of agency in discourses of treatment for youth with eating disorders

by

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## Abstract

This project analyzes the discourses circulating about young people with eating disorders (ED) in popular and legal materials. Through use of discourse analysis through a Foucauldian lens, I have determined major themes in how we make sense of involuntary treatment, in particular. In analyzing cases from the Ontario Consent and Capacity Board (CCB) and newspaper articles from *The Globe and Mail*, *Toronto Star*, *Ottawa Citizen*, *Ottawa Sun*, and *National Post* I drew out common narratives and themes. Agency, not surprisingly in the current medico-political context was noted throughout all texts, and was found to be alongside or in opposition to, discourses of protection. I drew out three themes which framed this overarching tension: (1) hospitalization experiences: outcome oriented approaches to treatment; (2) the family unit: a source of harm and care; and (3) the patient as a broken child. Legislative documents and regulatory frameworks were used to provide the backdrop upon which this discourse plays out. Youth with EDs are the bodies upon which these discourses are written, producing them as particular kinds of subjects. My analysis reveals that there remain fundamental tensions in how we understand the young person with an eating disorder and how they should be treated. Any progressive changes to legislation or health care frameworks must address these tensions around youth agency or they will merely reproduce the current issues.

Keywords: eating disorders, mental health, treatment discourses, discourse analysis, adolescents, childhood, youth, legal discourses, news media, media analysis

## **Dedication**

*For my number one fan, my Grandad, Eamon Keeley.*

*I could not have done this without your guidance. Your endless pursuit and acquisition of knowledge, and compassionate nature inspired me, and fueled this project. Thank you for always believing in me, and for your unconditional love and support.*

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## Chapter 1

### Introduction

Bright pink hair and making faces at the camera, 17-year-old Beth emerges on screen; likeable and obviously smart, she paints the picture of a person who is obviously competent and complex. In the documentary *Don't Call Me Crazy*, viewers are given an inside look at the lives of young people in the McGuinness Unit for Adolescent Mental Health in Manchester, UK (Dedman & Baker, 2013). Beth's struggle with anorexia nervosa is prominently portrayed as a mental battle with herself that she feels she is losing every time she succumbs to staff and eats even a morsel of food. It is reported that Beth entered treatment initially voluntarily, but was later enrolled in the involuntary program which facilitates more significant weight gain and subsequently better treatment outcomes.

The documentary portrays Beth's story brutally honestly, and demonstrates her situation is one of complexity, as she attempts to claim some semblance of agency while being treated as an in-patient. Watching the struggle of this bright person struck a chord for me, and I began to look into the issue of involuntary treatment for eating disorders in Ontario. What I noticed is that this issue is often framed as a fight for agency by various actors involved in the treatment process (Parker, 1994; Tan, Hope, Stewart, & Fitzpatrick, 2003). While youth are arguably at the bottom of the pyramid here, they certainly are not the only ones grasping at straws, trying to establish some form of control over the eating disorder (ED). Parents and frontline workers are heavily entangled in this narrative as well.

Parents seem to have slightly more agency than the child, in that they usually have the power to say yes or no to the treatment options of their child (DeMarco, Powell, & Stewart, 2011; Okninski, 2016; Sibeoni et al., 2017), but this is not an unfettered right or a

straightforward choice. Various structural mechanisms are in place that serve as a reminder to parents and their daughters<sup>1</sup>, that they are afforded this right under the assumption that they will do what is “best” for their child (Akre, 1992; Alston, 1994; Archard & Skivenes, 2009; Carbone, 2014; MHA, 1990; Ontario Child and Family Services Act RSO 1990 c C. 11, n.d.). Experts begin to come into the picture at this point, as they determine what is considered “best” for each patient they encounter (Mayer & McKenzie, 2017). Physicians arguably have the most power and agency of all actors on the front line, but they are bound to legislative frameworks that regulate this decision-making authority. Ultimately, the Ontario Consent and Capacity Board (CCB) acts as a final determinant in cases where mental health patients are held involuntarily in hospital for treatment (MHA, 1990). Patients appeal to the Board to revoke their status as an involuntary patient. These cases are a fascinating window into how EDs are conceptualized, and further how children and youth are constructed by legislative bodies and legal and expert discourses.

The most powerful actor in these cases is the eating disorder itself. Portrayed in many ways as a force to be reckoned with, intent on taking over the patient and their family, the ED is almost considered indestructible (Bowers, 2014; Cullen, 2010; Fisher et al., 1995). Physicians and experts grapple with a loose understanding of the disorder itself, and in this way are rendered somewhat powerless to it. There is no consensus on ED treatment, causes, symptoms, or even

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<sup>1</sup> EDs are diagnosed significantly more often in female adolescents, as opposed to male adolescents (there is almost no data about gender fluid adolescents). This is why I have said daughters, because it is far more likely. Boys are still diagnosed, but there are many conversations being had about why they are not as likely to be diagnosed with EDs. The reasons vary from biological explanations, to sociological implications of media messaging (Dr. Clare Roscoe, n.d.; Graham, 2011; La Rose, 2011). Female adolescents are at a much higher risk for ED diagnosis, regardless of the reasoning behind the diagnosis, and therefore it is crucial to think of the gender implications here. Girls and women have been conceptualized as vulnerable, in the same ways that children have (Bould et al., 2016; A. Harris, 2003; Hauge, 2009; United Nations & Inter-parliamentary Union, 2003; Wiederman, 1996). Many feminist movements from the beginning have also focused on childhood rights.

types of EDs, with constant updates being made to the existing typologies (Fisher et al., 1995; Sullivan, 2005). The variance within the narrative of ED experience is so individual that it would be difficult to claim that there is only one way in which it presents itself. Yet, for all its instability as an object of knowledge, EDs are very much part of popular consciousness given their high prevalence<sup>2</sup> in Ontario and the fearful way in which they are talked about in public discourse.

The popular and legal discourses surrounding ED treatment in young patients are fascinating, especially in relation to discussions of agency. There is an inherent tension between how we conceptualize the developmental stages of youth and adulthood (Berger, Hasking, & Martin, 2013; Schulman, 2006), and, as a result, there is a narrative of agency woven through texts addressing the treatment of EDs. These play out in accordance with broader current conflicts between youth protection and autonomy, yet emerge here in a visceral way. Youth engagement, a mainly autonomy driven discourse, encourages active participation from youth in decision making processes that directly impact them (Davidson & Manion, 1996; Pereira, 2007). It has become fashionable in youth health care discussions. Implementing youth engagement often requires adult-driven organizations to designate meaningful ways for youth to be more involved, shifting power dynamics and allowing young people to take up space (Checkoway, 2011; Pereira, 2007).

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<sup>2</sup> 5-10% of girls and women have an ED (Dr. Clare Roscoe, n.d.); 100% of the youth in the court cases I analyzed were female (see Appendix 1); “of people in treatment 1 in 20-30 are male” (Hopewell Eating Disorder Centre, 2013); in a 2001 study of adolescent EDs, out of 1739 adolescent females surveyed, 27% had ED attitudes and behaviours that would qualify them for intensive ED treatment (Jones, Bennett, Olmsted, Lawson, & Rodin, n.d., p. 1); “Eating disorders are predominantly found in girls and women with a female-to-male ratio of 9:1” (Martin & Golden, 2014, p. 1); “Girls aged from 15 to 19 years are at highest risk for eating disorders” (Martin & Golden, 2014).

Youth protection, on the other hand, is usually used as a justification for overriding youth engagement, in order to protect youth from harm (Aroni, 2007; Clough, 2016). Protection is at the base of most policies created for children and youth, often taking the form of “best interests of the child” (Archard & Skivenes, 2009). While both youth engagement and protection discourses may produce positive outcomes for youth, when they come together – which is often – I suggest they are not compatible. In fact, instead of reducing existing tensions and inherent power dynamics of how we think about the treatment of youth with EDs, I believe that these discourses have the potential to create or heighten these tensions.

The stakes of youth autonomy versus protection are particularly heightened in the area of eating disorder cases, which are particularly dangerous and prevalent amongst youth populations, with the most significant, direct, physical and mental health consequences. Sullivan found in a recent study that 10% of individuals diagnosed with anorexia nervosa will die within 10 years of onset (Sullivan, 2005). Eating disorders are more prevalent in teens aged 13-17 years of age, and most common in females in this age demographic (Hopewell Eating Disorder Centre, 2013; Martin & Golden, 2014; Public Health Agency of Canada & Canadian Paediatric Society, 2016). Involuntary treatment is often utilized in cases of eating disorders due to the nature of the illness itself (Bryden, Steinegger, & Jarvis, 2010; Cullen, 2010; Watson, Bowers, & Andersen, 2000). Youth being treated for eating disorders using involuntary programs exemplify the real world consequences of a clash between protection and engagement discourses.

When she is enrolled in the involuntary program, Beth tells the camera, “apparently it’s in my best interests and because I’m too ill, I can’t see what’s right for me. It doesn’t feel like that, which sucks” (Dedman & Baker, 2013). What is interesting is that the staff make a similar statement about the way that protection and youth engagement are conflicting: “she doesn’t think

people care, but because she's in a distressed state she's not seeing the real picture. Everyone's in a vulnerable state" (Dedman & Baker, 2013). Attempting to protect a young person in such a state of illness from further harm, while attempting to engage youth within treatment planning and implementation is no easy feat, and it may not be as simple as frontline workers listening to the opinions of youth (Clough, 2016; Davidson & Manion, 1996; Schulman, 2006). Procedures and policies based in the discourse of protection are the root issue for actors attempting to support youth in ED treatment, particularly those who are involuntarily committed.

Youth autonomy and protection discourses are coming together and playing out on the body and mind of youth with eating disorders, as well as the frontline workers who are dealing with the issue, and the parents who are involved (Brazier & Bridge, 1996; Brierley & Larcher, 2016; Harrington, 2016). In terms of youth engagement, open communication about the reasoning for specific treatment is being provided to Beth, which is a crucial component (Davidson & Manion, 1996; Pereira, 2007). However, the conversations between Beth and staff are also drenched in protection-related language when justifying involuntary measures. They draw upon the "best interests standard," commonly discussed in child studies literature as a key component of the formation of health care policies created to protect children from harm (Akre, 1992; Alston, 1994; Archard & Skivenes, 2009; Azer, 1994; Breen, 2002; Carbone, 2014; DeMarco et al., 2011; Diekema, 2004; Levesque, 2016; Okninski, 2016; Parker, 1994). Found at the intersection of these two necessary but often competing dialogues of protection and youth engagement Beth, and others like her, exemplify the real world consequences of this collision of frames that do not work together to reduce tension, but in fact create or intensify existing tensions. In this project, I explore these tensions and how they play out in Canadian legal and popular discussions of EDs

## Chapter 2

### Literature Review, Analytic Concepts, and Methodology

*Communication, whether spoken or written, will always involve discourse. An integral focus of health communication therefore should be the analysis of discourse as it related to public health concerns. Discourse analysis is a valuable way of understanding the underlying assumptions inherent in health professionals' communication with their clients, lay health beliefs and the messages and meanings about health issues disseminated in the popular media (Lupton, 1992, p. 149).*

My project sits at the intersection of a number of issues and draws upon and speaks to a variety of literatures in relation to eating disorders in youth: specifically childhood and adolescence; best interests of the child; youth autonomy; agency; media discussions of mental health; protection in policy; and power dynamics in youth health care. This chapter outlines the conceptual tools and understandings that are crucial to the construction of this project. Regulatory frameworks surrounding the treatment of patients with EDs are described in detail as a context for my analysis. The understanding of adolescence as a distinct developmental period after childhood, and prior to adulthood, is also essential to the analysis. Finally, I review my approach to discourse analysis.

#### Eating Disorders

As noted above, eating disorders are increasingly prevalent in youth ages 13-17 in recent years, and are seen more often in girls (Cullen, 2010; Fisher et al., 1995; Sullivan, 2005). In fact, a recent study argued that it is reaching the level of an epidemic in public health (Cullen, 2010). Hospitals are struggling to cope with an increased demand for services (Girz, Robinson, & Tessier, 2014; Payne, 2014a), while youth and parents are often at a loss as to where to turn when they are in need of support (Levac, 2014; Sibeoni et al., 2017; Ungar, 2004). Sociological research in eating disorders focuses on the ways that external factors of social experience

influence the development of eating disorders in adolescent girls. There is plenty of literature available on the role that schools, classmates, and teachers play in developing healthy relationships with food and attitudes towards body image (e.g. Abrams & Stormer, 2002; La Rose, 2011; Mueller, 2015).

Another major area of research covered sociologically in relation to eating disorders in youth is the importance of strong peer and family connections in preventing the onset of eating disorders or treating eating disorders post-onset (Choudry, 2008; Hoadley, Smith, Wan, & Falkov, 2017; Strober & Humphrey, 1987). Research on relationships between youth and their peers is currently being extended to online platforms such as Tumblr and other blogsites, where pro-anorexia pages are largely popular (Harper, Sperry, & Thompson, 2008; Nichols & Good, 2004; Yeshua-Katz & Martins, 2013). The media is also a major target of discussion in relation to eating disorders and policy given the perceived strong bidirectional relationship between the media and eating disorders in adolescents (Harrison, 2000; Norris, Boydell, Pinhas, & Katzman, 2006, p.; Reichel et al., 2014; Slavtcheva-Petkova, Nash, & Bulger, 2015).

The framework for treatment of EDs is complex. Mental health professionals are responsible for determining the mental capacity of the patient, and for deciding if they should be put in treatment against their possible verbalized wishes to abstain from treatment (*MHA*, 1990). Parents, on the other hand, face the difficult decision of whether or not to actively fight against their child's wishes to pursue treatment. Many parents feel that they do not have the information they need in order to make the best decision for their child's safety, and they do not know where to turn when they begin to have imminent concerns for their child's life. Often, they feel that the system works against them, in favour of their child's opinions (Armstrong, 2014; Thuncher, 2018). Meanwhile, youth are consistently struggling to be autonomous, and to have their

opinions valued in decisions that have a significant impact on their wellbeing rather than as passive actors (Brierley & Larcher, 2016; Davidson & Manion, 1996; Delman, Clark, Eisen, & Parker, 2015; Stasiulis, 2002).

While there is scholarly literature examining the ways in which involuntary treatment is conceptualized for each party (parents, workers, youth), there does not seem to be research on the commonality of these conceptualizations and experiences. Much of the literature on workers looks at burnout of the job itself (Barford & Whelton, 2010; Benner & Curl, 2018; Soderfeldt, Soderfeldt, & Warg, 1995). The literature about youth engagement and adolescent autonomy seems to look at autonomy and legal obligations of various stakeholders (Akin, Brook, Byers, & Lloyd, 2016; Borden L., 2016; Brazier & Bridge, 1996; Brierley & Larcher, 2016; Turrell, Peterson-Badali, & Katzman, 2011; Weithorn & Campbell, 1982). Further, no attention is paid to the ways that the disease and youth are framed and talked about. Scholars have overlooked the ways that how we talk about a social problem often significantly impacts how we understand and address that social problem.

Youth with mental illness are at an intersection of autonomy and care, in that they are fighting for independent decision-making authority in high stakes situations concerning their health, while suffering the symptoms of debilitating mental illness that in fact needs treatment. Frontline workers are invested in making sense of the complex situation, making quick decisions that will hopefully yield productive results in favour of the young person's wellbeing (Brierley & Larcher, 2016; Stanley, 2007). Literature indicates that frontline workers believe family oriented treatment, which incorporates all members of the patient's family in a model of care focused on engagement, is the most effective in treating eating disorders (Dr. Clare Roscoe, n.d.; Fennig, Brunstein Klomek, Shahar, Sarel-Michnik, & Hadas, 2017; Tan et al., 2003). However, there is

also a strong element of fear involved in the process of determining treatment, as physicians are often confronting a host of potential, or current, symptoms of physical deterioration. These symptoms often demand in-patient treatment, making youth and family engagement that much more difficult (Fennig et al., 2017).

### **Defining Adolescence in Discourses of Autonomy and Protection**

It seems that regardless of the discipline, adolescents fall within the age group of approximately 12 and 25-years-old, however the majority of the definitions end adolescence at 18-years-old. For the purpose of my analysis, I will be using 18 as the cap, due to Ontario hospital regulations which limit child oriented healthcare to this age range<sup>3</sup>. Adolescence itself is the developmental period of time between childhood and adulthood (Ben-Amos, 1995; Dubas, Miller, & Peterson, 2003; Galland, 2003). It is often defined as a period of development that is full of emotional turmoil and self-discovery (Casey, Getz, & Galvan, 2008; Ebata & Moos, 1991; Elkind, 1967; Hagan & Wheaton, 1993).

Much of adolescent-specific research explores what it means to be considered adolescent, analyzing the ways in which childhood is conceptualized at various levels of society (Brierley & Larcher, 2016; Casey et al., 2008; Elkind, 1967; Pharo, Sim, Graham, Gross, & Hayne, 2011; Worth, 2009). Adolescence and emerging adulthood has been conceptualized in many diverse ways across different scholarly fields and disciplines such as sociology (Abbas, 2017; Furlong,

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<sup>3</sup> The transition between child and adult health care systems is debated in many policy reviews in Ontario, it has been suggested by multiple agencies that the age of child and youth oriented treatment facilities be altered to encompass growing research that indicates adolescence extends well into the early 20s (Furlong, 2016; Randall et al., 2016; The Canadian Association of Paediatric Health Centres, The National Infant, Child, and Youth Mental Health Consortium Advisory, & The Provincial Centre of Excellence for Child and Youth Mental Health at CHEO, 2010; Yan, Wang, Behdinan, & Suryavanshi, 2017). While I surprisingly could not locate legislative documents to this effect, I was able to locate multiple major Ontario hospital websites specifying the age at which a child must discharge and move into adult services (Children's Hospital of Eastern Ontario, n.d.; SickKids, 2014).

2011; James & Prout, 2003; Kenneally, 2017; Mayall, 2000), psychology (Casey et al., 2008; Davidson & Manion, 1996; Pharo et al., 2011), education (Azer, 1994; Covell, Howe, & McNeil, 2008; Wilson, 2006), communications (Nichols & Good, 2004; Slavtcheva-Petkova et al., 2015), health sciences (Choudry, 2008; Fisher et al., 1995; Furlong, 2009; Mayer & McKenzie, 2017), social work (Handley & Doyle, 2014; Jack, 1997; Schelbe et al., 2015; Stanley, 2007), legal studies (Akre, 1992; Alston, 1994; Breen, 2002; Rix, n.d.; Sykes, 2006; Tan, Stewart, Ftizpatrick, & Hope, 2010) and of course within the relatively newly established field of child and youth studies (Abrams & Stormer, 2002; Checkoway, 2011; Hanson, 2014; Tuukkanen, Kankaanranta, & Wilska, 2012).

Through the formation and development of childhood studies as a discipline, into current research in the field, adolescent specific studies have started to become more prominent. Childhood studies is multidisciplinary in approach, drawing on fields such as psychology, law, history, and sociology to recognize childhood as a unique life stage worthy of analysis. Originating in the drive to further understand how we conceptualize childhood, internationally and across disciplines, childhood studies has grown since its establishment in the early 1900s by Stanley Hall (Dubas et al., 2003). In *Centuries of Childhood*, Philippe Ariès demonstrates how the psychological and sociological perspectives of family and childhood developed into fields of study in their own right (Ben-Amos, 1995). Since Ariès, the perception of childhood has not developed much from the picture of the innocent child, corrupted by adult imposed harshness. However, it has expanded to include many interpretations of the lived experience of childhood (James & Prout, 2003; Pinkney, 2011). With this expansion comes evolving definitions of specific periods of development within “childhood.”

On the policy front, incorporating youth and children is sometimes created as an add-on to adult related policies. In some domain there are policies to specifically address young people, for example Canada's *Youth Criminal Justice Act (2002)*. Youth policy research has begun to move in the direction of shifting power from the hands of regulatory bodies to the hands of those they are attempting to regulate (Colley, 2003; Pereira, 2007; Schulman, 2006). However, this shift is slowly and incrementally occurring, and seems to be built around structures of compliance still to this day (Kennelly & Llewellyn, 2011).

Most youth-related policies are aimed at protecting children from negative experiences, attempting to maintain what is thought to be the natural state of childhood – blissful happiness and innocence separated from a harsh adult world (Ataiants et al., 2017; Breen, 2002; Charlow, 1986). The concept of control is prevalent in literature about children and childhood, including power dynamics based on the, arguably incorrect, argument that young people do not possess the maturity or language necessary to make informed decisions (James & Prout, 2003; Schelbe et al., 2015; White, Wyn, & Albanese, 2011). Children are perceived to be molded by adults in their lives, designed to grow *into* a functioning member of society, rather than currently existing as a citizen prior to adulthood (Galland, 2003; Worth, 2009). Policy research in regards to young people is heavily based in the assumption that children require protection from any potentially harmful influence, sometimes through any means necessary, due to their perceived lack of understanding about the situation at hand (Archard & Skivenes, 2009; Aroni, 2007; Charlow, 1986; Clough, 2016; Hanson, 2014; Pinkney, 2011).

This is a hard position against which to argue because it advocates for universal protection of children and youth. However, many child advocates and researchers focus on shifting the perspective from protecting the vulnerable, which implies a lack of ability in

children, to empowering young people to be active citizens currently (Aroni, 2007; Checkoway, 2011; Checkoway et al., 2003; Covell et al., 2008; Gilligan, 2009; Kennelly & Llewellyn, 2011; Stasiulis, 2002, 2002; Tuukkanen et al., 2012). Researching policies that regulate aspects of youth lives requires attention to the many ways that children's voices have been cast aside, but with careful attention not to dismiss the voices of those who have a significant investment in the lives of children (e.g. parents)(Hoadley et al., 2017; Tan et al., 2003; Ungar, 2004). The complex power dynamic of parent(s) and child(ren) is constantly navigated, debated, and analyzed in youth policy research (Duncan, Drew, Hodgson, & Sawyer, 2009; Sykes, 2006). Further the inherent power dynamics between physician(s) and child(ren) are explored in similar ways, due to the importance of the relationship in the therapeutic setting (Robinson, Boachie, & Lafrance, 2013). Compliance and competency are often difficult to untangle, as adult stakeholders expect obedience in the form of their expertise being unconditionally respected and accepted by young people. This compliance is portrayed as synonymous with the "good child" in comparison to the "bad" or "troubled" one (Clough, 2016; Nichols & Good, 2004; Rix, n.d.).

For example, Kennelly & Llewellyn (2011) explore education curricula in Canadian high schools on government and citizenship. They utilized discourse analysis to evaluate current claims being made about the active citizen in civics curriculum documents used by teachers for the purpose of educating high school students on civic engagement (Kennelly & Llewellyn, 2011, p. 901). The focus throughout their analysis is on the ideological language in these documents, and they emphasize the ways that active citizenship has been defined by regulatory forces which create such documents (Kennelly & Llewellyn, 2011). They found that alongside encouraging active engagement, curriculum documents consistently warned of the dangers of breaking social norms, laws and rules within their respective provinces. The authors tie this issue

to neoliberal styles and tools of governance by making strong connections between specific word pairings, and by showing the absence of certain phrases that would cause more radical change or support rebellious behaviour in the eyes of a capitalist system (Kennelly & Llewellyn, 2011). They demonstrate that even when ‘progressive’ changes are made towards youth autonomy, these discourses are often more complicated with counter-forces of disempowerment and discipline still at work. This narrative of compliance also relies upon traditional depictions of children as vulnerable, innocent blank slates.

The construction of children as vulnerable is prominent in various aspects of discourse surrounding youth in general, and particularly youth with mental health struggles (Breen, 2002). Defining children as defenseless is a unique form of violence against the very people it claims to protect in that it solidifies the structural power imbalances between children and adults (Gilligan, 2009). Defining a term, such as “child” that is heavily based in individualized experiences is complex and difficult. The *United Nations Convention on the Rights of the Child (UNCRC)* states that any person under the age of 18 is considered a child, which is limited in that it relies solely on age and excludes other contributing factors (The United Nations, 1989). The category of childhood is almost universally recognized to include protection from harm.

This attempt to “shelter” children subsequently omits those who do not feel they fit the narrow socially constructed definition of a child despite being under the age of 18. Young people with EDs often fall within this alienated group, as they do not fit definitions of childhood that demand innocence, pleasantness, and compliance (Abbas, 2017; Bryden et al., 2010; Hanson, 2014). When universal definitions for childhood are used in protective policies, it systematically excludes “atypical” children. This is a form of discrimination, often referred to in childhood studies as “childism” (Young-Bruehl, 2012). Creating a clearly defined category for childhood

serves to relax adults, making them feel as if they are doing their duty to protect the best interest of the child (James & Prout, 2003; Thorne, 2009). These classifications are problematic when put into practise. The challenges of a definition of childhood makes policy creation for and with young people quite a complicated process.

It is well documented that adolescents are in a developmental phase of egocentrism. Egocentrism includes such phenomena as the imaginary audience and the personal fable (Elkind, 1967). This phenomenon is well supported in research (Casey et al., 2008; Elkind, 1967; Galland, 2003; Pharo et al., 2011; Worth, 2009). It is also well supported that when pushed or educated, youth have the capacity to consider those around them just as much as they consider their own well-being and situation (Checkoway et al., 2003; Covell et al., 2008). Young people have shown that they have goals to better the world around them, and more specifically, they have shown serious concern for bettering the lives of other young people (Covell, Howe, & McNeil, 2008; Tuukkanen, Kankaanranta, & Wilska, 2012). This indicates that while youth and children do conceptualize the world around them as it impacts them directly, they also have concern for others and are able to understand others as separate from themselves. In fact, research has shown that young people are often the first to point out inequality and are sharp in their observations of visible discrepancies between themselves and peers (Covell et al., 2008).

In developing frameworks to support the empowerment of youth, the concept of youth engagement emerges. While definitions of this concept vary across the available literature, it is generally agreed upon to be a theoretical framework upon which youth oriented policies are built to guide frontline work. Youth engagement models have emerged in mental health organizations for youth over the last 20 years, largely due to a study conducted by Ian Manion and Simon Davidson (1996). Their study indicated a lack of meaningful youth empowerment and

engagement in services that directly impact their wellbeing, and as a result an increased feeling of hopelessness in an existing state of mental illness (Davidson & Manion, 1996). In this spirit, the Ontario Centre of Excellence for Child and Youth Mental Health recently created a youth engagement guide for mental health organizations across Ontario based on research conducted on the current state of affairs in this area (Pereira, 2007).

Youth engagement emerged, as most child and youth policies do, partly from the *United Nations Convention on the Rights of the Child (UNCRC)*, specifically Articles 12 and 13. Article 12 describes the child as “capable of forming his or her own views” and Article 13 describes the child as having “the right to freedom of expression” (Pereira, 2007; United Nations, 2006).

The term ‘youth engagement’ is an emerging concept that does not possess an universal definition. In the literature many scholars use the terms ‘participation’, ‘volunteerism’, ‘partnership’, ‘involvement’, and ‘engagement’ interchangeably. In contrast, organizations that research and promote youth engagement regard these terms as being independent of one another and have spent time developing specific definitions for youth engagement (Pereira, 2007, p. 11).

Interestingly, while youth engagement is extremely prominent in public discourse, and on many organizational websites serving young people for mental health issues, it does not have a consistent definition across organizations. Even leaders in the field of youth engagement seem to disagree on what constitutes this term and model. Pereira (2007) describes organizations as open and willing, publicly, to support youth engagement but ultimately unsure of how to do so within the current social and political landscape.

The Centre of Excellence for Youth Engagement presents youth engagement as “the meaningful participation and sustained involvement of a young person in an activity that has a focus outside of him/herself” (Pancer et al. 2002 in Pereira, 2007). This seems to be the driving research organization in youth engagement in Ontario. Most of the research they have done is in the Ottawa, Cornwall, Brockville and Kemptville areas of Ontario, and tends to be focused on

training staff in youth-oriented organizations in how to better facilitate youth programs (Pereira, 2007). Mental health programming has come into the spotlight as of late, due to increases in cases among children and youth (Malla et al., 2016; Martin & Golden, 2014; Payne, 2014a).

From the available academic literature, it seems that research on youth engagement in mental health treatment is focused almost exclusively on suicide (Ramey et al., 2010). The following quotation is from a prominent study on youth engagement in treating suicidal teens.

Youth engagement comprises affective (e.g. enjoyment), cognitive (e.g. perceived control), and behavioural (e.g. frequency of involvement) components... At the interpersonal level, activity engagement has been linked to greater connectedness in family relationships, including greater parental trust and attachment... Youth engagement has also been associated with better quality of peer relationships and more positive peer networks... highlight the importance of intrapersonal and interpersonal factors as potential processes through which activity engagement is linked with positive outcomes for youth (Ramey et al., 2010, pp. 244–245).

In my project, youth engagement is one of many elements of a broader discourse around youth autonomy. I draw upon and adhere to the above definition.

The discourse of protection is particularly prominent in youth related policy documents, as well as dominant in social talk about youth mental health. Often when discussing the option of placing a young person in involuntary mental health treatment, parents are at the forefront of the conversation as they are often responsible for the wellbeing of adolescents in their care. While the decision-making capacity of adolescents is a widely debated issue, it actually does not seem to enter the conversation as much as expected when it comes to research on involuntary commitment. Instead the concept of protection from harm seems to command the most attention in the scholarly literature. Specifically in relation to eating disorders, which seems to be the classic example utilized in cases of debating involuntary commitment.

A young person can lack competence to make a decision even if they have the capacity, that they have an underlying condition which means they lack capacity, such as anorexia

nervosa that an otherwise competent decision may be overridden by a person with legal authority if it is their best interest to do so (Brierley & Larcher, 2016, p. 4)

Brierley and Larcher's research comes the closest to acknowledging the relationship between protection and autonomy in youth mental health. Almost as an endnote to their paper they proclaim: "it may be that absolute autonomy and freedom of choice are inconsistent with the protection rights that society has agreed are owed to children" (Brierley & Larcher, 2016, p. 4).

One of the most universally used and accepted justifications in children's rights and health care alike for intruding on the autonomy of young people is the "best interests of the child." The *UNCRC* was one of the first regulating documents to put forth the concept of the "best interests of the child," Article 3, as a guiding principle for all decisions made in relation to and for children (Kenneally, 2017).

The *UNCRC* has been largely criticized for its western-centric perspective (Kenneally, 2017). It is quite significant that the major guiding document for children's rights legislation across many nations in the world is critiqued for holding a narrow view of childhood. This allows for gaps to exist that cause further harm to children, based on the fact that they are not applicable within certain contexts, and provide a stark difference between the reality of these children and the 'ideal' childhood experience. In this way certain policies further marginalize children, due to the lack of engagement with constructive critiques of the *UNCRC* as a whole.

Throughout this thesis I refer to people under the age of 18 as per the *Ontario Child and Family Services Act* (Ontario Child and Family Services Act RSO 1990 c C. 11, n.d.) as "patients." I was attempting to find a neutral term that could be used to discuss people in this life stage in order to avoid the obvious associated tensions between the words child, youth, teen,

adolescent, and kid. While I understand that patient is, in and of itself, a loaded term<sup>4</sup>, for the purposes of this discussion I wanted to avoid the moral valences often attached specifically to child and youth in public discourse. The one exception to this is in Chapter 5, “the patient as a broken child”, in which the discourse *itself* treats the patient as a child and as a troubled teen. In this case, the use of the words child and teen are used as part of the analysis as they are in play.

Overall, research in the field of youth policy currently seems to be positioned towards expanding on notions of youth autonomy and empowerment while maintaining the importance of stakeholders within the community.

### **Regulatory Frameworks**

The general information provided above is meant to provide the international and general backdrop upon which these regulatory frameworks have been painted. In this section, I will provide an overview of the specific regulations in place in Ontario for ED patients.

Children and youth are regulated differently than adults in official streams of power; by utilizing the *UNCRC* various authorities are able to construct laws and policies aimed at specifically supporting and protecting the child. The *UNCRC* provides a base document from which most subsequent legal and human rights documents stem (Kenneally, 2017). The “best interests of the child” standard is pervasive in nature, spanning the entire Convention. In fact many provisions of the *UNCRC* are dedicated to explaining the ways in which the “best interests of the child” should be utilized in relation to all other principles laid out within the Declaration.

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<sup>4</sup> The word “patient” situates the subject in a particular position and environment in which they are inherently weaker than physicians.

Interestingly, the first few pages lay out the ways in which various regulatory powers should be utilizing the best interest principle. The document highlights the individualistic nature of deciding what the “best interests of the child” are, on a case by case basis. However it does not define processes that can help determine what this looks like in various cases, nor is there a clear definition of what “best interests of the child” should be.

More significantly, there is no articulation of adolescent autonomy in relation to the best interests principle. The recognition of adolescence as a separate period of development (Casey et al., 2008) which may warrant more decision-making power is not articulated in the Convention. It claims to specifically address issues in relation to children, which is defined as individuals under the age of 18 (The United Nations, 1989) and no effort is made to understand that long span of human development as staged. Other legislative documents choose other ages to represent the shift to adulthood, ranging from 16-19, as they designate the “appropriate” age for young people to be allowed to participate in various activities such as driving (Highway Traffic Act, 2018), drinking (Liquor License Act, 2017) and voting (Election Act, 2017).

In Ontario, there is no officially designated age of consent when it comes to the presumption of capacity. In other words, young people do not have the initial privilege of being presumed capable of decision-making, but rather they can be treated as presumed *incapable* and need to prove otherwise. There is specific legislation in the *Mental Health Act* which specifies that a patient who has been found incapable with regards to treatment must be formally informed of their rights by a rights adviser *if they are 14 years of age or older*<sup>5</sup>. There is no specification

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<sup>5</sup> Section 15 (1) under Rights Advice for Patients Found Incapable with Respect to Treatment of a Mental Disorder. “If a person who has been admitted to a psychiatric facility as a patient is 14 years old or older and if the person’s attending physician proposes treatment of a mental disorder of the person and finds that the person is incapable with respect to the treatment within the meaning of the *Health Care Consent Act*, 1996...”

about people who are 13 years of age and younger; it is left up to the judgment of the physician to determine how or if the rights adviser will be contacted. This implies that some patients who are committed involuntarily are not immediately given access to a rights adviser.

In the *Mental Health Act (MHA)*, the mental health criteria for involuntary and voluntary patients is outlined in detail to provide legislative guidance to physicians and mental health professionals. In order to determine status of the patient, their capacity or lack thereof must be demonstrated by the psychiatric physician on the case. Particularly in cases of involuntary commitment, the presumption is that the patient is capable of making competent and informed decisions in regards to their care. If there is a challenge of this capacity, the onus is on the physician to prove otherwise. In order to do so, the physician must complete “Form 1: Application for Psychiatric Assessment.” In this form, they must satisfy requirements from Box A (see Appendix 2) and/or Box B (see Appendix 3) to be put forth for a full assessment.

If any other member of society has reason to believe that an individual is not of sound mind, and wishes to have them evaluated and held for treatment of a mental disorder, they would complete a Form 2: Order for Examination (see Appendix 4). In this case, they would present their case to a Justice of the Peace, and provide evidence as to why the individual of concern meets the requirements outlined in Form 1 from either Box A and Box B. The police are then able to apprehend the individual and bring them into mental health custody for the purpose of psychiatric assessment, at which point a Form 1 would be completed by the mental health physician.

While a Form 1 is still in effect, the physician conducts a thorough assessment of the patient in hospital. The attending physician decides based on observational assessments, if the person should be admitted involuntarily. The observations of the attending physician lead to the

decision to: admit the individual with involuntary status by completing a Form 3 Certificate of Involuntary Admission (see Appendix 5) which provides grounds for an involuntary finding; or admit the individual with voluntary status; or release the individual from the treatment facility.

The first certificate of involuntary admission (Form 3) is restricted to 2 weeks, the physician then re-evaluates the status of the patient. If at this point the patient is still in need of psychiatric treatment, a Certificate of Renewal (Form 4) is completed, which adds an additional month. After this, another evaluation occurs and if more time is deemed necessary then another Form 4 is completed, which adds an additional 2 months. Following this extension, another evaluation takes place, and if the patient is not yet ready for voluntary status, then another Form 4 is completed, which adds an additional 3 months. At the end of the third certificate of renewal, if more time is needed, the patient is subject to a Form 4A which is reviewed by the Consent and Capacity Board (CCB)<sup>6</sup>. Under the *MHA* the physician who applies for a Form 1 must be a different physician from the one who completes a Form 1 that leads to a Form 3 in order to establish that more than one medical professional supports the need to involuntarily commit the patient. All patients are entitled to challenge the decision of involuntary status and bring the case before the CCB for review, the attending physician is required to notify the rights adviser who will then meet with the patient to inform them of this right (MHA, 1990).

The *Health Care Consent Act (HCCA)* is primarily concerned with determining capacity in the areas of treatment decisions, admission to care facilities, and personal assistance services. This provides a framework for informed consent and findings of capacity, as well as parameters for service delivery and treatment (Health Care Consent Act, 1996). There is an extensive and

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<sup>6</sup> The CCB is an independent provincial tribunal, which was created under the *Health Care Consent Act* in order to conduct hearings in relation to consent and capacity issues (“CCB,” 2015). In relation to eating disorder patients, the CCB reviews involuntary status of patients, capacity to consent to treatment, and surrogate decision makers.

comprehensive definition of: consent, capacity, emergency treatment, liability, and procedures for applications to the board in Part II, Treatment (see Appendix 8). Consent elements are clearly defined to include the expressed or implied consent of patients, with regards to starting and continuing treatment. They clearly define in Section 14 that a person must be able to withdraw their consent at any time. All of these elements rest upon the finding of capacity in the patient. If the patient is not found to be capable of decision-making, the *Substitute Decisions Act SDA* is invoked, and a substitute decision maker (SDM) is appointed to the patient. Usually this is a family member, who is deemed capable. The grounds for capacity and types of individuals that can be appointed SDM are provided in the *HCCA* under Section 20 (see Appendix 9).

The *Substitute Decisions Act (SDA)* is generally utilized in this context alongside various components of the *MHA* and the *HCCA* to provide legal parameters for appointed figures to act on behalf of the patient, for the duration of their involuntary commitment and finding of capacity. The *SDA* also regulates SDMs for property disputes. SDMs are defined in detail through-out Part II, The Person. The SDM is almost always the parent/guardian of the child, in cases of involuntary treatment for EDs in children and youth. In the *SDA* definitions are provided for each type of possible SDM, as specified in Section 20 of the *HCCA*. It is also specified that in order to be a SDM, the person must be “at least sixteen years old” (Health Care Consent Act, 1996, c. 30, s. 44). Which is incredibly ironic, given the limited access to their own rights that someone has at this age. In Section 32, Duties of guardian, the best interests of the patient are defined as:

Best interests

- (4) In deciding what the person’s best interests are for the purpose of subsection (3), the guardian shall take into consideration,
- (a) the values and beliefs that the guardian knows the person held when capable and believes the person would still act on if capable;
  - (b) the person’s current wishes, if they can be ascertained; and

(c) the following factors:

1. Whether the guardian's decision is likely to,
  - i. improve the quality of the person's life,
  - ii. prevent the quality of the person's life from deteriorating, or
  - iii. reduce the extent to which, or the rate at which, the quality of the person's life is likely to deteriorate.
2. Whether the benefit the person is expected to obtain from the decision outweighs the risk of harm to the person from an alternative decision.

This gives a very specific definition of “best interests” when it comes to surrogate decision making processes. This is never referred to in court cases in my corpus, despite the obvious relevance. In fact, “best interests” are specifically named as irrelevant to court decisions from the beginning of each case. This rests on case law, citing *Starson v. Swayze*, SCC 32, 2003 as grounds for dismissing best interests, due to the finding in this case that the best interests are supposedly “irrelevant” to the determination of capacity. It is interesting that there are contradictions across legislation and court decisions.

The literature reveals the tensions present surrounding involuntary treatment, particularly of young people. ED patients exhibit arguably the highest tension, given the high prevalence and consistent seriousness of the disorder's diagnosis. The demographic of young people with EDs, tends to be young females, and in this way gender is wrapped into the discourse inherently. Youth with serious EDs, facing involuntary commitment in Ontario, are facing an excruciating process, alongside family and physicians, they exemplify the real world impact of the tensions discussed above. The discourses surrounding this tension in popular and legal texts, are my primary focus for this thesis.

## Discourse Analysis: Knowledge and Power

Instead of gradually reducing the rather fluctuating meaning of the word ‘discourse’, I believe I have in fact added to its meanings: treating it sometimes as the general domain of all statements, sometimes as an individualizable group of statements, and *sometimes as a regulated practice that accounts for a number of statements*. (Foucault, 1972, p. 80) [emphasis added]

Foucault provides the base upon which my discourse analysis is built with the above definition of discourse, in which statements are subject to regulations, and language interacts with regulation. Discourse can also be perceived as “something which produces something else (an utterance, a concept, an effect)” (Mills, 2004, p. 15). The way we talk about things, contributes to the construction of truth in relation to concepts. An example discussed in my analysis is the comparison between alternative medicine and Westernized medical approaches utilizing medications, in which alternative medicine is deemed irrational. This is also discussed in Sara Mills’s book on discourse analysis, when referencing the work of Norman Fairclough:

“alternative” knowledge about health is not given the same status as conventional medical science; a great deal of effort and discursive work is expended on ensuring that alternative medicine is considered inferior, amateurish and as falling within the sphere of charlatans, thus maintaining for medical science the authority of the “true” and the “scientific”. Thus, discourses do not exist in a vacuum but are in constant conflict with other discourses and other social practices which inform them over questions of truth and authority. (2004, p. 17)

Discourse is therefore inextricably tied to social location, and notions of power and knowledge. These notions are not concerned necessarily with what is real and what is true, but rather with the depictions and constructions of knowledge and power using language (Mills, 2004, p. 17). Through the Foucauldian lens, power is not viewed to be a possession that one can have, but rather that power is “dispersed throughout social relations, that it produces possible forms of behaviour as well as restricting behaviour” (Mills, 2004, pp. 17–18).

Discourse analysis relies on the assumption that language and speech are inseparable from social life, based largely in Foucauldian thought (Mills, 2004; Taylor, 2013; Wodak & Meyer, 2001). This type of analysis calls for an in-depth analysis of both physical texts, and the context in which they are situated environmentally, historically, and socially (Mills, 2004, p. 10). Discursive analysis challenges the very concept of objective knowledge, suggesting that there is meaning in every social process and questions the ways that language and socially circulated knowledge interact (Taylor, 2013).

Knowledge is conveyed through language in ways that are often patterned, despite the established idea that meaning is context specific. Foucauldian interpretations of knowledge rely on the strong connection between knowledge and power. Foucault does not conceptualize individuals as “oppressed by power relations” but instead views them to be the “effects” of power relations (Mills, 2004, p. 19):

The individual is not to be conceived of as a sort of elementary nucleus... on which power comes to fasten... in fact it is already one of the prime effects of power that certain bodies, certain gestures, certain discourses, certain desires, come to be identified and constituted as individuals. (Foucault, 1978 in Mills, 2004, p. 20)

In this way, youth with EDs are considered constructed to be vulnerable, rather than oppressed by discourses of vulnerability. Discussing power dynamics in relation to the creation of these depictions of actors dealing with a patient who has an ED, is crucial to understanding the legal conceptualizations of youth in this position.

According to Deborah Lupton, discourse analysis fills an existing methodological gap in communications research in public health, by providing an analysis that is critically aware of the social location of the issue being studied (1992, p. 148). Providing an analysis that pays attention to the documents through which we circulate meaning about medical issues and which goes beyond quantitative accounts of word usage, are much of what makes my project different from

other studies done in the field of mental health research. With this in mind, I conducted an in-depth discourse analysis utilizing three main categories of documents: legislation, newspaper articles, and cases from the Ontario CCB.

Discourse analysis provides a method of understanding conceptualizations of particular social groups and phenomena through an in-depth analysis of language. Discourse analysis has the goal of exploring the characteristics of how knowledge is made about particular objects in ways that actually constitutes those objects as capable of being known, rather than revealing detailed information about the formation of speech or text structure (Blommaert & Bulcaen, 2000; Taylor, 2013). The discussion of power is prominent in literature describing this method, and the ways in which language and power work together, and against each other, to produce ways of knowing that shape how subjects are understood in the world. I am using discourse analysis to provide a picture of the state of the public and legal conversations around youth mental health policy at various levels in the contemporary Ontario context. Discourse analysis is uniquely positioned to explore the places where power and dominance are heavily debated and contested, which is a constant thread of children's rights research (Archard & Skivenes, 2009; Kenneally, 2017).

### **Building the Corpus: Procedure and Criteria**

Given the wide range of interests in analyzing language, knowledge, and power and the ways these intersect, collecting and analyzing 'data' in discourse analysis projects can be a complex process. Researchers doing discourse analysis have to make the decision early on in their process what kind of information they will be interested in for their research question. These decisions will determine if the researcher requires new data such as interviews, focus

groups or recorded conversations, or if they will be using existing textual traces such as regulatory documents, advertisements or newspaper articles (Taylor, 2013). In relation to my project, from the start I knew that I would like to analyze the discussion of youth mental health treatment by focusing on newspaper articles and court cases.

The concerns of discourse analysis, however, and the insights it provides into the complex relationship between the audience and text, interpersonal communication between individuals, health beliefs and behaviours are directly relevant to public health in its mission to understand health and illness in their sociocultural context, and its role as a provider of health information (Lupton, 1992, p. 149).

This excerpt points to the clear bidirectional relationship between media and health care, and the ways that discourse analysis of media sources can inform meaningful research in the field of mental health care.

Youth engagement as a dominant discourse of child and youth mental health, as previously discussed, emerged mainly from the 1996 study by Ian Manion and Simon Davidson. Their study sparked the interest of many scholars in the field of youth mental health treatment, particularly in the province of Ontario. The establishment of youth engagement oriented organizations such as Youth Net, which was, and still is, a partially CHEO funded organization in Ottawa. There were multiple satellite locations of Youth Net set up in other provinces such as British Columbia and Quebec; however none of the other sites lasted long, arguably due to lack of funding directed at youth engagement oriented organizations. Ontario's approach to "for youth, by youth" organizations specifically created for the purpose of supporting young people with various struggles including mental, has served as a model for other provincial developments that are still a work in progress (Pereira, 2007). Across Ontario the discussion on better involving youth has been at the forefront of conversations in the media and on the frontline. This is why I have decided to focus on Ontario for my project.

A search of major Ontario newspapers *Ottawa Citizen*, *Toronto Star*, *The Globe and Mail*, *The Ottawa Sun*<sup>7</sup>, and *The National Post* was conducted using the search terms: Eating Disorders, Anorexia, Anorexia Nervosa, Bulimia, and Mental Illness. I used the databases Factiva, Canadian Newsstream, and LexisNexis. This provided a large number of articles to sort through. I decided to include any articles that pertained to people between the ages of 12 and 18 years old, as this age group is the most commonly diagnosed with eating disorders, and is generally defined to be an adolescent or child (Cullen, 2010; Dr. Clare Roscoe, n.d.; United Nations, 2006) and thus most likely to be caught up in the complex nexus of protection and autonomy. I limited my search to the years 1996 onwards, due to the discussion of youth engagement becoming especially articulated and prominent in this year with Davidson & Manion's (1996) study of youth in mental health care. The decision to only look at Ontario, was to match the Ontario CCB, which is where I chose cases from. I ended up with 98 articles from various newspapers that fit my project needs.

I used CanLII to find Ontario CCB cases, in which young people were appealing their involuntary status. This seems to be a particularly high tension dynamic, and uniquely narrates the process of ED incapacity findings from the perspectives of multiple actors in a legal context. I searched for the term Eating Disorder, because in order to hold a patient involuntarily, symptoms of a disorder must be present currently or in the past (MHA, 1990) and the other terms I used in my newspaper search all fall under the category of an eating disorder in clinical terms (American Psychiatric Association, 2013). This search yielded just over 1600 results. At this point I looked at the first few pages to locate the introduction, where the age of the patient is

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<sup>7</sup> This was included to provide a tabloid, in order to see if they speak differently about the topic than mainstream news.

always stated. When I determined they were 18-years-old or under, I downloaded the case into a file on my computer. Once I had gathered all of the cases that met the criteria, I printed them and began reading.

In order to analyze the texts I had sorted through, I looked for specific traits in the dialogue. Initially I looked for discussions of autonomy, and youth engagement. I began to notice other prominent themes emerging. After this initial immersive reading, I began to do more purposeful readings, in which I read looking for a specific theme or type of wording (e.g. ED as a monster, depictions of illness as unstoppable). Articulating the themes in discursive terms became the analytic chapters of my project.

### Chapter 3

#### **Hospitalization Experiences: Outcome Oriented Approaches to Treatment**

*The evidence portrayed CP as a very challenging patient to treat. She was described by Dr. Proulx and indeed presented as intelligent and quite knowledgeable about her illness and proposed treatments. She presents as sincerely wanting to comply with treatment and remain in hospital to receive treatment. (CP (Re), 2017, p. 10)*

The hospitalization experience is at the forefront of the discourse across newspaper articles and court cases, particularly the ways in which the hospital and the patient interact, as well as the scripts for how people are expected to be acting when within hospital settings. The treatment process often relies upon eradicating symptoms that are caused by EDs. These symptoms are significantly amplified to emphasize the ways in which the hospital system is failing, or in order to exemplify the patient's lack of capacity. Progress and improvement are often minimized in order to further solidify that the young person is incapable of long-term improvement. In these ways, power is being utilized to create the effects of panic and fear through language that is specifically constructed to produce this effect. The previously mentioned discussion of carefully constructing certain subjects to be lesser than others, is a discursive phenomenon in which we see the impact of language play out in the real world. At the heart of the discourse around treatment is a meticulously created feeling of fear that is attempting to drive changes on a micro and macro level in the area of ED treatment.

#### **Inciting Fear as a Potential Vehicle of Change**

An overarching goal of improving conditions for those suffering from ED symptoms and their families is consistently present across newspaper articles and court cases. Fear is used to attempt to motivate social actors towards these changes. This manifests in an attempt to achieve some form of power over the illness that is currently running the show for all people involved.

The system that supports patients with EDs is also targeted in the panic-inducing phrasing, as a center of untapped potential, and obviously a source of power and control. I have divided my discussion of the hospital experience as catalyst for change into two sections: (1) catastrophizing symptoms and minimizing progress and (2) panic and fear based narratives of physicians, systems, and families.

### ***Catastrophizing Symptoms and Minimizing Progress***

*L was focussed on what she perceived as the treatment team's expectation that she would fail. She felt that she had not received credit for the progress that she had made in her recovery so far, which she attributed to her motivation and perseverance. Away from hospital, she said, she had no issues regarding food. (L (Re), 2009, p. 10)*

A pattern of catastrophizing symptoms using excessive and negative adjectives emerged consistently and repeatedly across the various texts in my corpus. Reports of symptoms taking over the formerly healthy child span newspapers and cases. A lack of support systems to treat patients is particularly highlighted in the media, utilizing panic to attempt to mobilize concerns and catch the eye of powerful figures. Many times, lengthy lists of symptoms or potential side effects are described in great detail, while success is minimized in some way. In the following excerpt, the behaviour of the patient is described as an example of her instability and mental incapacity:

*She had at least one big blow up with her mother over the holidays. Knowing that she had this hearing and wanting her involuntary status rescinded, JS had an incentive to stay safe over the holidays. Dr. Nguyen said that despite making some therapeutic progress at CAMH, in the last month JS had disengaged and become oppositional with staff. (JS (Re), 2018, p. 15)*

Particularly of interest here is the quick mention of progress in contrast with great detail on the negative aspects of JS's behaviour.

The inclination to breeze past progress in favour of lengthy and detailed descriptions of problem areas, highlights certain types of behaviours that support an involuntary ruling. In another case, *L (Re)*, 2009, the patient is accused of minimizing her symptoms:

The Panel found as a fact that L continued to minimize the severity of the effect that her ED continued to have on her, and that she was exaggerating the progress made so far in dealing with it. This was somewhat understandable, given the fact that she was now at 100% PW [progress weight] and did not look like someone suffering from an eating disorder. But an eating disorder is a mental disorder, and low weight is just one symptom of it. (p. 11)

Many things about this jump off the page. First, the fact that L reaching the predetermined healthy weight based on biological factors (p. 4) was quickly mentioned and immediately contradicted with a flimsy statement that L “did not look like someone suffering from an ED.” Second, that weight is considered “just one symptom of an ED” despite countless references across cases, including this one, to low weight as *the* determining factor of a presenting ED.

Emphasis is constantly placed on weight to indicate the unhealthy status of the patient. It is often over-emphasized in order to make the point very clear that the patient is ill enough to be involuntarily treated.

Dr. Boyer further had concerns about Ms. B’s bone density, her reported density being equivalent to a fifty year old woman, fertility issues, disruption of menstrual cycle and a number of other symptoms such as gastrula-intestinal issues, poor healing wounds, loss of growth potential Osteoporosis. (*B (Re)*, 2005, pp. 3–4)

The comparison of this young person to a 50-year-old woman, in terms of bone density, is likely an attempt to show the extreme nature of the physical symptoms this patient is facing. While of course these are all quite scary to hear, they are even scarier when they are listed one after the other. Further, they induce fear with the narrative comparison between a young person, who is supposed to be the epitome of health, and an old person who is declining in health and possibly ill. This lends itself to the argument that symptoms are not exactly exaggerated, but rather are

catastrophized in that they are painted to be at their worst, and contributing to a sense of inevitable doom of the patient.

This is not exclusive to the court cases, in Kates & Kates, 2003 (p. 3) the writer, a parent of a child with a severe ED, describes the experience of having a daughter who refuses to enter hospital care: “That means we should let go. But we can’t. Not now. We cannot let our daughter kill herself. So we continue to watch what she eats, beg her to eat more, and force her to get weighed weekly. To no avail.” Based on these descriptions, it is safe to conclude that catastrophe is imminent or occurring, and the symptoms are evidence of this. This excerpt is an example of another relevant pattern the evaluation of symptoms, risk of imminent death. Many times the imminent risk of death is posed as the ultimate consequence to releasing the patient from involuntary treatment. The death of anyone is of course tragic, but the death of a young person is mourned more intensely by the public at large, and by families (Christ, Bonanno, Malkinson, & Rubin, 2003, p. 20).

The disease is called deadly in many instances, and it is often used in cases to show the imminent risk of death that the patient would face if they were not held involuntarily in hospital. In *AA (Re)*, 2015 the Board presents the opinion of the treating physician Dr. Isserlin at the Children’s Hospital of Eastern Ontario:

The primary concern was the risk of serious physical impairment should she released because, as has been the consistent pattern, AA would resume behaviours that have caused obvious physical impairment and required hospitalization; indeed, if her disorders are left untreated there is even the risk of death. As to when such risks would be likely to materialize if the patient were released and left untreated, Dr. Isserlin said the occurrence of such consequences would be “imminent”. (p. 9)

The imminent risk of serious harm and/or death is consistently mobilized, particularly in court cases as evidence of incapacity.

The following excerpt is from *JQ (Re)*, 2011 (pp. 12–13) in which the Board is explaining why it has decided to uphold the involuntary status of the young person JQ:

JQ in her own testimony was not prepared to provide an unequivocal response to the question about whether or not she would stay in hospital if made voluntary. She stated in response to that question, “I would not leave the hospital - at least not at this point”. She left the question open and the Panel was not persuaded that she understands the need for treatment and therefore the need to be in hospital to obtain such treatment.

The patient states that she would not leave the hospital at this point when asked if she would continue treatment at this hospital. This is a clear response to the question, and leaves room for this decision to change for a variety of reasons that could present themselves. Yet the reason that is given for the upholding of her involuntary status is that the Board did not feel “persuaded” by her response. What is particularly interesting about this exchange is that, despite a clear answer that indicates intention to stay, the Board still did not feel comfortable affording decision-making power and agency to this patient. The fact that even slight doubt of the patient’s compliance with treatment leads to the confirmation of incapacity indicates she does not have the right to make decisions regarding her health or even to contribute to them in a meaningful way.

A complete removal of the patient’s agency is at play, when they are not even afforded the possibility of making an informed decision for their health. In fact, in the press and cases, the discourse is centered around the conceptualization that young people have *too much* agency in the hospitalization process. For example, in the *Ottawa Citizen*, a journalist writes “It doesn’t help that Jenna is of legal age and can call the shots. Unless she falls so ill that she is declared mentally incompetent, her parents have no say in what she has to do to get better” (Adami, 2015, p. 3). Decision-making power never lies in Jenna’s hands, yet the news media say that they can take this power away when she is ‘sick enough.’ The false construction of the patient’s legal right to make decisions regarding her health is meant to testify to holes in the healthcare system.

The disease itself is painted in a negative fashion, possibly for the same purpose. For example, in a *Toronto Star* article about ED treatment in Toronto, Alamenciak (2013) quotes a medical expert: “These people are like in a living death, and they just go on indefinitely until they die,” said Dr. Blake Woodside, an expert in EDs with Toronto Western” ( p. 3). The description of the illness as “a living death” is quite grim and presents a dark perspective on the disorder as a whole. Further the fact that it is a quote from a purported expert in the field, can induce fear in the target demographic of readers: parents.

Death is at the forefront of the discourse, and is considered to be not only the worst possible result, but also to be imminent for those with EDs. The fear of this outcome is manipulated by press and in cases, possibly to gain sympathy for patients and support the purported need to protect them by any means necessary. Sometimes, parents explicitly express their concerns with the health care system in this area, which I will now dive into with my next section on panicked parents and physicians.

### ***Fear and panic: Narratives of physicians, systems, and families***

Panic and fear are at the heart of the narrative for parents of children in hospital, and inducing these emotions is universally practiced across platforms and perspectives. The provocation of parents in order to trigger specific emotions that require a concrete response is evidently the objective. In this case, the reader is not positioned at a safe distance from the problem; they are placed in the center of it, with relatable situations and characters. It is obvious that these depictions of EDs in newspapers will be primarily read by parents, and in fact the majority of these articles are also written by parents. Many parents describe situations in which the health care system fails them or does not support their ‘right’ as a parent to put their child

into treatment without their express consent. The fear of the hospital is that they do not have the resources to properly support rising numbers of young people coming into hospital for mental illness related issues. Either way, the issue of young people sick with EDs is evidently deemed something to be very concerned about, and the discourse reflects this.

Newspaper articles rely on parental reports in order to gage the effectiveness of the health care system in relation to their child's wellbeing. For example, in *The Globe and Mail* article in which a mother recounts the experience of supporting their daughter through multiple layers of treatment, she describes the desperation she begins to feel as the treatments fail her daughter: "There isn't any more resource to throw at this and nothing's working. My child, my beloved, is starving herself to death. Most days I am surprised that I function at all: How do you live with a broken heart?" (Kates & Kates, 2003, p. 3). This language invites fear and pathos in the reader, particularly those who are also parents of adolescent girls. The plea resonates with anyone who has felt heartbroken and exhausted in the face of illness. At the mercy of an illness that cannot be controlled, it draws attention to the frustration of a parent, watching their daughter crumble before them. Further, it is an example of panic-inducing language, as it targets this specific demographic, and hopes to inform people of the lack of available resources in the community.

Another newspaper article from the *Ottawa Citizen*, tackles this particular issue, when the health care system is blamed for the relapse of their teenage daughter:

Her parents feel the health system has let Jenna down. She is still waiting to be referred to a psychiatrist, 2 ½ years after she was told she needed one. They say Jenna's wait for a psychiatrist has only allowed her disorder to fester. Her mother says she personally believes that had a psychiatrist been available to treat her daughter immediately after her release from CHEO, she may not have relapsed. (Adami, 2015, p. 4)

Even the possibility that Jenna would not be as sick if the system were different is obviously tragic. This type of framing, with assumptions about what could have been, reveal a panicked

mother attempting to convince someone to pay attention to the problem. The push for more services and shorter wait times dominates the discussion in the media around ED treatment for youth.

The sharing of personal stories is utilized to show just how dire the situation is, and framed in a way that shows it can happen to anyone, at any time, in order to attempt to force people to pay attention to the issue. In the Kates & Kates article, the comfort of hearing that this panic is justified, is provided: “If you’re worried about your child’s eating patterns, ‘the very fact your mind is going there means there probably is a problem,’ says Ann Kerr, program director for Sheena’s Place in Toronto, a support centre for people with eating disorders” (2003, p. 6). Directly aimed at parents, framed in a discussion-like tone, the appeal is made for parents to pay close attention. Reassurance is given, and the push for parents to pay attention to their child shifts the blame from the systems in place, to the parents of the sick child. The subtle nod in the direction of parents being the gatekeepers of their child’s health, confirms that parents who are worried, should be.

The age of the patient with the ED is one way in which the discourse in media and courts promotes fear to make change happen in the treatment community. The younger the patient, the more emphasis is placed on how horrible it is to have an ED. Further when an ED presents in full force in a person under 16, it is surprising to doctors both in court cases and in newspaper articles. In the *Ottawa Citizen* the concept of children with serious ED symptoms is presented:

“It used to be you would see eating disorder patients coming in middle adolescence. We are now seeing them as young as eight or 10, presenting with a full-blown eating disorder.” She also said the hospital is treating children as young as 10 who are cutting themselves - something that used to begin about age 16 or 17. (Payne, 2016a, p. 3)

The implication is that it is not as serious for a 16 or 17-year-old to be self-harming or suffering from a “full blown” ED. Age is also utilized to exemplify the lack of supports available. For example, in the following 2009 *Toronto Star* excerpt:

“Eating disorders are the third most chronic illness in adolescent females, but children affected are getting younger and younger,” says Meryll Bear, program director for NEDIC [National Eating Disorder Information Centre]. Symptoms can occur in girls as young as 5, she said. (Winsa, 2009, p. 2)

An emphasis on the fact that EDs can occur in children younger than 16 is meant to convey the seriousness of the issue and its poignancy.

Another relatively prominent feature of the discussion that emerged was the physician’s hesitation to label a young person being stated in cases. Physicians are unwilling to formally diagnose a young person with a mental illness, because it is typical for older age groups (Harrison, 2000; Levac, 2014). When an illness is known to be more prevalent in a specific age group, it becomes significantly more weighted to diagnose a younger person with that illness, because it implies that the disorder is so severe that it was diagnosed years before typical onset. This is commonly seen for personality disorders, because the *DSM-5* provides diagnostic criteria that are often typical of adolescence itself (Courtney-Seidler, Klein, & Miller, 2013). Therefore, if an adolescent is diagnosed with a personality disorder before the age of 20, it is viewed to be automatically more severe, and increasingly so as they grow and develop, due to its early onset (Sharp, Tackett, & Oldham, 2014).

For example, a doctor in this particular case, when talking about the time it took to receive treatment, spoke of the diagnostic difficulties associated with being a physician: “Dr. Nguyen stated she was very reluctant to prematurely “label” a fifteen year old” (*GB (Re)*, 2012, p. 5). The fact that many doctors are seeing increases in younger patients with these diagnoses should indicate that it is not at all premature to diagnose a 15-year-old. However, it is still stated

that the doctor felt reluctant to diagnose the patient. This is in direct contradiction with the often page long list of diagnosed physical and mental illnesses that are brought before the court. For example, a 16-year-old, RJ, is described as having multiple co-existing disorders:

Exhibit 2, Psychiatric Assessment by Dr. Spettigue described issues on multiple axes. The MSE can be simplified as follows:

Anorexia

Severe social anxiety

Severe generalized anxiety

Paranoia Psychosis? secondary to the eating disorder vs primary

PTSD

Substance Use Disorder

R/O Bipolar disorder, history of depression, SI and mania

R/O OCD (obsessive worries are likely secondary to anxiety plus low weight)

Somatic delusions (hypochondriasis)

(*RJ (Re)*, 2017, p. 6)

This type of list of symptoms is often used as evidence of the severity of the situation for the patient, and emphasizes their incapacity. By listing off multiple issues of the patient, the incredibly difficult job of the physician is performed, because the assumption is that all of these conditions need to be fixed. It also inadvertently increases the number of people who will identify with the story of the individual.

An increase in adjective use and the amplification of affect can be noted when describing younger people with EDs.

At 10, the Ottawa girl's weight loss was *so pronounced*, her state of dehydration and vital signs *so worrisome*, that her doctor sent her *directly to emergency* at the Children's Hospital of Eastern Ontario. There she *stayed for weeks* while her *alarmed* family remained by her bedside. (Payne, 2014, p.3, *Ottawa Citizen*) [emphasis added]

This is alarmist language. Instead of saying that the girl's health had deteriorated significantly, the writer chose to repeat the word "so" and add adjectives that paint a picture of a desperately ill child and devastated family.

Another way of emphasizing the severity of the issue as a social problem in the discourse is through the use of statistics that make it appear as if an eating disorder can, and often does, happen to anyone – even the best people. In the following case, in a section that outlines evidence of the patient’s inability to appreciate the reasonably foreseeable consequences of their decision or lack thereof, parents give their opinion on what the consequences are likely to be:

Parents describe this teenage girl as not being able to organize herself or be able to initiate a task, i.e. they express concern about her ability to care for herself. They say that recently she cannot cook or work or do schoolwork or housework or basic hygiene (*in contrast to the lovely, bright, talented, accomplished competent girl she was up until grade 8*). (AA (Re), 2015, p. 10) [emphasis added]

Newspapers especially capitalize upon available statistics, mostly cited from the Hopewell Eating Disorder Centre’s website from the early 2000s. These statistics set the scene of an ominous and widespread situation that continues to claim the lives of young people. Take, for example, this excerpt from the *National Post*: “One in four adolescent girls in Canada displays severe symptoms of eating disorders such as bingeing, gulping diet pills and self-induced vomiting, according to a new study” (Vallis, 2001, p. 1). One in four implies that there are teenage girls that every reader knows, or knew, that suffers from this type of illness. Further, the selected symptoms of some eating disorders are those that are most severe. For example, instead of saying distorted thinking about food, which is arguably the most generalizable symptom across types of EDs, they have selected bingeing and purging as well as taking pills. This particular selection pattern is not just seen here, but is similar across newspaper articles and cases alike.

The use of adjectives such as “gulping diet pills” and “severe” in combination with such a high prevalence rate, is enough to strike fear into any reader, particularly a parent. This type of language relies on the reader’s sense of responsibility to assist those suffering and to do

everything possible to stop the spread of EDs before it hits someone that the reader knows. In this way the horror can act as a mechanism of potential social change as it invites these feelings in the general public and, presumably, increases the possibility of community stakeholders investing in funding the treatment of the issue. EDs get constructed as a widespread, rather than specialized, social problem. Experts contribute to the construction of the ED in popular discourse as well as legal discourse, when they provide their opinion on specific cases or the state of ED prevalence in society at large. In my next section I will provide detailed accounts of the expertise discourse.

### **Expertise, Protocol and Procedure**

Staff often justify their qualifications to the court in their testimonies about the patient. These doctors are not always the ones who are brought into court as expert witnesses, in which case it makes sense to justify the use of that individual. It is the attending physician assigned to the case of the patient that is listing their qualifications, or having them listed by others. For example: “A team that included Dr. N. Johnson and Dr. J. Couturier devised this treatment plan. Dr. Johnson is a pediatrician at McMaster hospital who has specialty training in eating disorders” (*NZ (Re)*, 2012, p. 8).

Interestingly, credentials are equally as prevalent in newspaper articles, where journalists typically include all of the education and credentials the perceived expert in the field, in order to justify their selection of that particular individual. For example in the *Toronto Star*, a journalist discusses the results of a study that parallels symptoms of binge-eating disorder with bulimia and justifies the opinion of a relevant expert:

While Canada wasn't one of the countries surveyed, Dr. Allan Kaplan, senior scientist and chief of clinical research at the Centre for Addiction and Mental Health (CAMH) and vice-

chair research for the University of Toronto's department of psychiatry, said results would likely be similar. (Gerster, 2013, p. 2)

This claim justifies the use of a Canadian doctor when talking about a non-Canadian study. It is interesting that instead of selecting one relevant credential such as the fact that he is in fact a psychiatric doctor, they list multiple elements of his résumé. It almost feels as if the writers who do this are attempting to mediate the chaos of a relatively unpredictable illness by showing that there are experts in this field who are extremely specialized and working hard for a solution. The credibility of the experts is presumably present in newspaper articles, to suggest that this person should be heard by the public and officials. It is also plausible that the expertise is meant to provide comfort to readers, who may be feeling fear and panic.

Another interesting component of the expertise discourse is the need for people to respect the 'facts' as presented by the experts whose qualifications are so clearly articulated. When a patient or parent disagrees with the plan of the treatment team, typically the physician, this disagreement is often used against them in determining the capacity of the patient or their surrogate decision makers, almost always parents. For example, below, the Board describes a patient who refused treatment, in hopes of pursuing less invasive means than feeding tubes:

the Board found that although she was articulate and informed, JK was unable to apply the risks and benefits test of the proposed treatment to herself in a meaningful way. Her stated objections to treatment were not the reasonable conclusion of weighing the risks and benefits. She failed to appreciate fully and give weight to the grave, potentially life-threatening risks of refusing the proposed treatment. She did not appreciate the benefits of treatment. *She even questioned the value of treatment, contrary to expert medical opinions from Drs. Nowicki and Pinhas.* The Board found, on the balance of probabilities, that JK failed Part 2 of the test of capacity. (*JK (Re)*, 2014, p. 11) [emphasis added]

The final remarks, in the confirmation of incapacity based on the inability to meaningfully understand consequences to refusing treatment, are about the patient asking questions about the

value of her treatment. This shows the importance of complying with the orders of physicians on the case who are deemed (and demonstrated) to be expert medical professionals.

### **Coercive Treatment Discourse**

There are multiple examples of the use of coercion in the treatment of EDs, particularly using tube feeding during refeeding processes. Interestingly, these are described as ways in which the patient is denying themselves appropriate treatment that maintains their wellbeing. Coercion in the medical context is defined here as any actions that influences decision making of the patient with the goal of steering the patient towards specific types of treatment. In the discourse, typically coercive actions such as the forceful use of ‘treatments’ (including forced feeding using physical restraints and nasogastric tubes) are framed as evidence of incapacity on the part of the patient. For example, in the following quote, the Board uses this example as one piece of evidence towards the patient’s inability to see the potential consequences of restrictive eating:

*At hospital she only eats when there is a “threat” of a nasal tube feeding and even then tries to hide food in the garbage even when being directly supervised during feeding and after. The day of the hearing she tried to avoid her fat by “forgetting”, her salad dressing. (B (Re), 2005, p. 8) [emphasis added]*

Notably the court document puts ‘threat’ in quotation marks to indicate that the threat was perceived by the patient and was exaggerated in the use of this term. They also put the word ‘forgetting’ in quotation marks, to indicate that the patient did not forget to eat salad dressing, but purposely did not eat it. These small, not so subtle, linguistic indicators that the patient is exaggerating or deceiving the treatment team are used to justify the use of more severe and invasive measures. The word threat occurs surprisingly often across the corpus, for being such a loaded word in the context of medical ethics.

Further, the idea that one type of treatment can be considered required is interesting in the context of healthcare, as it is meant to be a largely self-elected process in which the patient consents, or not, to undergo specific treatments.

Dr. Couturier states that she in fact *became so mentally unstable that she required a nasogastric (NG) tube* inserted as she was to eat and was at imminent risk of suffering from cardiac arrest. Dr. Couturier stated *that she pulled the tube out later that night and it had to be re-inserted using restraints.* (*JQ (Re)*, 2011, p. 9) [emphasis added]

The fact that NG tubes are referred to as a must-use resource, is interesting as well, given that they are considered so controversial in other contexts, such as prisons (Del Rosso, 2018) and camps. In this passage from the *Toronto Star*, force is described as an inevitable requirement when the patient's health is declining: "Sterenberg's daughter, Amanda van Ryswyk, weighed 79 pounds when admitted in December to Homewood. At the time, the 16-year-old's pediatrician told the family Amanda was two weeks away from requiring tube feeding, Sterenberg says" (Kelly, 2008, p. 3).

The frequent casual mention of these methods (almost every case mentions NG tubes at least once and it appears in newspaper articles almost as often) draws our attention to the ways in which treatment has been defined in hospital and court settings. The goal of the treatment team, and often the family of the patient, is to completely eradicate symptoms of the ED by any means necessary. The comfort and consent of the patient is not particularly addressed in any of the discursive sites. Their lack of agency is written onto their bodies and the 'acceptable' treatment of them. The wellbeing of the patient is seen as a long-term goal that can only be achieved when the ED has been completely cured, rather than a consistent goal on a day-to-day basis that is possible even without full recovery.

### **Doctor/Patient Communication Styles**

*Ms. NZ said that she does not feel well enough to go to school because the pain is debilitating and she finds it hard to concentrate. When questioned about the possibility that anxiety is the cause of her abdominal pain she denied that that was possible. When questioned about her relationship with the hospital's treatment team she said that no one is listening to her and thus she is not telling the staff about what really ails her. (NZ (Re), 2012, p. 11)*

The experience of hospitalization is largely shaped by the healthcare professionals who work on the front lines in ED treatment. The patient is portrayed as reliant on the physician in court cases especially to determine their state of wellbeing and physical health. I have noted two dominant depictions of doctors in the discourse that are structured and framed in relation to the central binary of the best interests of the child vs. respect for agency and autonomy.

First, there is the figure of, what I call, the dictatorial communicator, which I define as a physician who decides the appropriate treatment plan on their own accord, or as part of a team, far removed from the patient's influence. The second figure I call the democratic communicator, defined as a physician who actively demonstrates their intention to involve the young person in the decision-making process when deciding on treatment plan elements. Rarely do the physicians appear in the discourse presenting themselves as dictatorial but actually acting as a democratic communicator. There are, however, occasions in which the physician is performing the role of the democratic communicator, but the surrounding descriptions of their actions reflect the actions of a more dictatorial communicator.

### ***The Dictatorial Communicator***

The dictatorial communicator figure places emphasis on the resistance of the patient in treatment, and the frustration they feel when they cannot convince the patient to 'do what is best for them' or to comply with recommended treatment. The dictatorial communicator embodies the hierarchical power relations between patient and treating professional. The physician may be attempting to demonstrate a democratic approach, yet ultimately succumbs to the dictatorial

narrative that structures their doctor-patient relations there and elsewhere. These physicians consistently emphasize the way they *tried* to teach the patient about themselves, to no avail. Words that highlight the power of the physician over the patient are used when describing the creation of the treatment plan. For example:

In hospital she *negotiated* with her treatment team over what her weight ought to be, over how quickly she should gain and over how many calories a day it took to achieve the goals *they set for her*. She spilled her drinks and *left too much* of the food *Ms. Woodcock prescribed*. (*AS (Re)*, 2006, p. 9) [emphasis added]

The word “negotiated” implies that the patient is attempting to find a way to alter a prescribed plan, rather than participating in a discussion with two valued opinions. The other words emphasized above indicate that the patient’s treatment plan was one completely constructed by experts, with which she is expected to comply. The arbitrary judgement of what is ‘too much’ leftover food, and the unfounded implication that this girl purposely spilled drinks, indicates the level of power the treatment team has over the patient’s treatment plan.

Dictatorial communicators are unwilling to answer questions about the approach they are using, and closed to alternatives. The questioning of doctors has been brought up in previous sections (e.g. Section 1.B: Expertise, Protocol and Procedure) and it emerges again in this depiction of physicians. Any patient who suggests a non-medicalized approach to treatment is highlighted as incorrect and even, outrageous. All of the medicalized terminology available is utilized and built up, to show that the patient’s request to avoid medications or try less invasive methods (e.g. naturopathic remedies, therapy, nutritionists) is painted in a way that makes the patient sound irrational. For example in (*H (Re)*, 2011):

Dr. Norris testified that [Ms.H] “struggled immensely once integrated into the day program. In many ways, we moved backwards not forwards.” He said *she needs both psychological and pharmaceutical intervention* if an effective plan for her is to be found. He said “*she cannot engage*” and “*she really needs medication because she’s too far gone*. We’ve done all that was possible to help her without medication.” (p. 5) [emphasis added]

Sometimes the professional explains that they tried all other methods possible before resorting to medicalized methods. However this still negates the patient's opinion about medication use; the concern is not meaningfully addressed, but rather is quickly considered before returning to the opinion of the physician.

The physician's opinion in dictatorial communication is often grounded in various numbers and statistics that are paraded out one after the other. Formal names for medications, used to treat various aspects of EDs, are also provided, possibly to emphasize the clinician's familiarity with medicine. This has the effect of medicalizing the issue in favour of the expertise of the doctor and creating a justification for their manner. An example of a dictatorial representation is found below, in which the physician testifies about the need to reach prescribed goals:

Dr. Couturier said that she wanted to get her [the patient's] body weight to 100 % of the correct body weight for her. She said the criteria for anorexia was 85% and that many people were not stable at 85%. She said that even if CS [the patient] ate solid food at 3500 calories per day, "it would be a miracle". She said that even eating at that level, olanzapine would be absolutely necessary for CS as it would prevent her from crying for hours, as she presently did, and would curb her aggression with her mother and father. (*CS (Re)*, 2017, p. 7)

The criteria for anorexia is 85% of the average body weight for the age and size of the patient (American Psychiatric Association, 2013), yet the doctor testifies that she wants the patient to reach 100% of the *correct* body weight. The explanation is offered that many do not function at 85%, which is to be expected given it is the established threshold for diagnosis of an eating disorder. However, the remaining 15% is unaccounted for in this explanation. The goal being a 100% perfect outcome, may be unreasonable in a chronically relapsing disease and is clearly objected to by the patient in other areas of the case.

It is not uncommon to see patients arguing that the expectations set for them are too high, and rely heavily on medications that they feel will alter their bodies or minds in significant and permanent fashions. These concerns are rarely addressed in the court cases or newspaper articles as reasonable, but rather are used against the patient in determining their capacity. Further, the physician describes her own treatment plan as so difficult to achieve that it would “be a miracle” if the patient were able to achieve it. This type of expectation shows the dictatorial doctor to be out of touch with the patient they are treating, and unrealistic about the expectations they set.

It is clear that the dictatorial style of treatment is prevalent in court cases, all of which were inpatients challenging the renewal of their involuntary status. It is interesting that there appears to be a relationship between appealing involuntary status, and dictatorial communication styles.

### *The Democratic Communicator*

Another kind of communicator figures in the discourse as well, although less frequently. These professionals are portrayed as respectful of patients and expressly articulate a desire to communicate with the patient when creating the treatment plan. The discourse conveys the view that the health of the patient should in fact be a responsibility of the patient rather than of the parent or physician. The autonomy of the patient is not debated, but is clearly considered a crucial component of building beneficial treatment plans. Tellingly, there is only one legal case in which a purely democratic communicator appears. However, there are legal cases in which the doctor is represented as democratic in their approach, yet their final decisions demonstrate dictatorial tendencies.

The only case in which purely democratic communication style is demonstrated in, is *SJN (Re)*, 2006. In this case, one way in which the communication style is demonstrated is through comments about the decision making power of the patient in relation to other actors involved (e.g. nurses, dieticians). The following example shows the active role that the patient was allocated, and what this treatment team describes as meaningful engagement.

After being admitted to hospital, SJN was *allowed to design her own meal plan in consultation with the dietician*. This is a feature of the HSC eating disorder program at HSC. SJN was not eating sufficient calories to gain weight and staff psychiatrists were carefully reviewing her overall treatment capacity. (p. 4) [emphasis added]

Here the patient's opinion is given weight in the discussion of treatment planning in relation to staff psychiatrists and dieticians. While the patient is monitored, as any reasonable person would expect, they are also given an active role in their own treatment process.

Another example within this case is the indication of working out agreements between patient and treatment team that clearly outlines the expectations of the patient:

SJN spoke of an agreement she had worked out with Drs. Bryden and Pinhas. She said that the agreement provided that she had to be "going in the direction" of gaining 1 kg weekly as a precondition to being discharged from hospital. She said she believes she can do this on her own but will remain in hospital because she does not want to take the risk of failure. SJN said that by the time she was at TEGH [Toronto East General Hospital] about six weeks ago she realized that she had to gain weight and was committed to this. (p. 5)

The patient agrees to gain weight steadily, or work towards the goal of steady weight gain in order to be released from the involuntary status she currently has. It further indicates the patient's commitment to fulfilling her agreement with staff. These types of agreements are indicative of the responsibility placed on the patient to take ownership of their treatment process, which depicts the physician as a democratic communicator. It is stated that a conversation took place that required agreement on both ends of the conversation, which mediates the inherent power dynamic of doctor-patient relationships.

In terms of cases in which the treatment professionals perform democratic communication style, but end up confirming a dictatorial approach, there are many more to choose from. In many legal cases, the discussion with the patient's behaviour is used as justification for not engaging in treatment discussion and planning. For example:

She presented herself as a quiet and thoughtful young woman at the hearing and did not appear to have any significant deficits which were obvious to the Panel. Dr. Couturier stated that when she attempts to discuss the proposed treatments with JQ that she stands throughout the interview and fails to focus on the information being provided to her. (*JQ (Re)*, 2011, p. 13)

The fact that JQ stood during a discussion is used to confirm that this patient is unable to communicate about the illness, or perceive the depth of the illness, is very interesting. It indicates that physicians and legal decision makers are willing to rely on body language to make substantial generalizations about the patient's capacity. This suggests that while the doctor says they engaged the young person in a discussion, the discussion was one-sided in nature. The doctor had decided that JQ is incapable of focusing on the information, prior to providing the opportunity to engage in conversation.

Many of the legal cases have quoted physicians stating that the patient was not able to talk about the situation, prematurely deeming them incapable of conversing. For example:

With respect to counsel, Ms. F. was so embraced by the disorder any discussion about the various aspects of the treatment plan would have been meaningless. She was unwilling throughout her admissions to discuss any element with the physicians and continued to maintain there was nothing wrong in her behaviours. (*BF (Re)*, 2005, p. 9)

The prediction that the conversation would have been "meaningless" is concerning, as it suggests that the treatment team has not attempted to engage the patient. This is almost completely coercive in nature, as it implies no informed consent. Saying that they would have engaged her in discussion if she had let them, is an attempt to appear democratic despite dictatorial actions of

deciding everything for the patient, from the start. These processes effectively render the patient voiceless.

## Chapter 4

### The Family Unit: a Source of Harm and Care

*Because it's an adult program, the doctors at Homewood talk to her, not to us. All decisions are hers. I find this terrifying. If I am not in charge of her health, who will be? ...She decides to take charge of her life. In this shift is the seed of her recovery. She starts gaining weight. I see now that she had to leave me in order to do this. (Kates & Kates, 2003, p. 3)*

In my corpus of socio-legal talk about EDs and involuntary treatment, the family is discussed as a source of harm and of care for the patient, and the level at which the family is considered crucial to treatment is very present. I offer a heuristic quadrant of the issues in which I suggest most cases fall (see Figure 1 on p. 54). The Support Quadrant provides four ways in which the family is framed in news and legal discourses in relation to the treatment of ED patients.

For the purposes of this project I limit my definition of the family to the patient's parents. Throughout the legal cases and newspaper articles, they are the most consistently discussed in relation to the patient's agency and decision-making power. While I acknowledge that the siblings of the patient are often heavily involved and impacted by the process of treating an ED, I will not address the role of siblings in this thesis. Other family members tend not to emerge in the discourse at this particular level. 'Parents' here refers to a mother and father who hold responsibility for their child who is a patient. Often the mother and father are grouped together as "the parents," unless they are providing testimony, in which case they are referred to as the mother or the father of the patient.

While there were more mothers visible in the newspaper articles, the father is almost always mentioned in relation to the family's wellbeing. In legal cases, both mothers and fathers are mentioned fairly equally, and are always discussed. The "partnership" is always a part of the conversation in relation the wellbeing of the patient. There were no same-sex parents in the legal

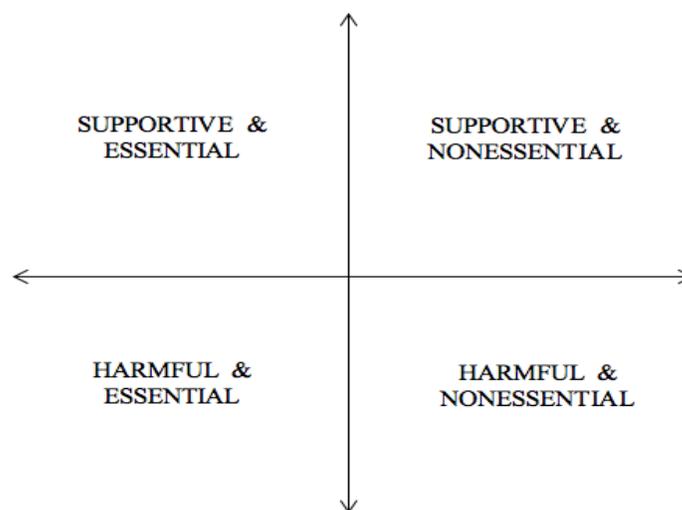
cases or newspaper articles in my corpus. There were some cases of single mother headed families, but this was not significantly relevant to the discussion at hand. The relationship of gender between parent and child is not discussed in this thesis, although I suggest there are interesting possibilities here for future research.

The family is a prominent part of the discourse, likely due to the fact that family-based treatment is one of the most promising forms of ED treatment for young people (Dr. Clare Roscoe, n.d.). In fact, this exact statement is brought up in multiple court cases, to explain why the family is taking charge of the patient's circumstances. For example:

OP has very limited food intake that does not meet her energy needs. Prior to her first admission, OP was restricting to 500 calories per day and her body weight had dropped to about 65% of her ideal body weight. Since then, her family had attempted to take control of her meals per the Family Based Treatment protocols which have the best evidence for treating Anorexia Nervosa. However, OP continues to refuse to eat adequately. (*OP (Re)*, 2017, pp. 5–6)

The use of family based therapy is described in multiple court cases, often as a first choice, that has not proven effective for the case of this patient. I created a spectrum upon which I believe parents fall, called the Helpful Parent Spectrum (see Figure 2 p. 65), where they are categorized to be assisting the physician or enabling the child to varying degrees.

## The Support Quadrant



**Figure 1.**

The family is discussed as the source of both harm and care for the patient, and the level at which the family is considered crucial to treatment is very present in the texts. My Support Quadrant provides four main categories in which the family is conceptualized in the discourse (see Figure 1 above). To determine where the parent falls, there are two main considerations. First is the horizontal axis which indicates where the parent falls between dichotomous terms ‘essential’ and ‘nonessential’ to the treatment process. Second is the vertical axis which indicates where the parent falls between dichotomous terms ‘supportive’ and ‘harmful’ to the wellbeing of the child in general, and especially in crisis.

While some parents fall squarely in one quadrant (e.g. supportive and essential), there are many cases in which parents fall somewhere in between. The place of the parents on the axes is not fixed; it varies based on the described actions of the family as the treatment progresses. The positioning of parents is highly normative. An example of the goal to move from a starting placement into another quadrant, is found in the following excerpt from a capacity case:

The long-term benefits of treatment were a better outlook on education, employment, socializing and *family relationships*. JK would have a better mental attitude and physical

energy to resume a more satisfying lifestyle. She would not have her life disrupted by frequent emergency hospitalizations and would not have to curtail activities due to poor energy levels. (*JK (Re)*, 2014, p. 7) [emphasis added]

The goal of the actors involved is to move the family into the gold standard of supportive and essential in order to best support the patient. When these bonds are broken, it is crucial to push the family into a “better” quadrant: “When asked about the importance of AA’s relationship with her parents, Dr. Spettigue agreed that their visits are ‘positive’ for AA and may help to improve a relationship that has seriously deteriorated” (*AA (Re)*, 2015, p. 14). This movement from categories such as harmful, but essential, such as the one mentioned here, is depicted as beneficial to the patient’s overall wellbeing. There is a judgemental undertone to all of the cases that fall outside the range of supportive and essential. The discourse invites others to judge the families that have failed, the “bad” parents who have contributed to the downfall of the patient.

### ***Supportive and Essential***

The supportive and essential family is represented as one that offers support to the physician and the patient. This family is described as an idyllic unit of love and protection and is essential to the patient’s treatment and growth. It is often utilized in newspaper articles to emphasize the ways in which the family is impacted by the patient’s ED. In legal cases, it is utilized to demonstrate how “far gone” the patient currently is and that it is in fact an issue of nature not nurture.

The ED is portrayed as a negative influence in the life of the patient and the family that is hurting the family dynamic which is otherwise, ideal. Sometimes the parents are portrayed as a necessary part of the treatment plan, often as a method of surveillance. In this legal case the parents are supporting the physician’s wishes, and the patient’s wellbeing, by watching the child

who is not in hospital: “The family physician advised CS to stop attending physical education classes at school, and CS’s parents began accompanying her to school for supervision over lunches” (*CS (Re)*, 2017, p. 5). The physician in this case, and many others with this type of parent(s), is even described as a family physician, not just the patient’s attending physician. The implication is that the doctor is treating the entire family, despite the ED’s individual nature. The family is deeply entangled in the treatment, as if they themselves are experiencing symptoms of the illness. The role of the parents in the above-mentioned legal case is to be a supervisor, ensuring that the child adheres to the plan of the physician.

The physician is not the only actor that implies the inextricable nature of the family and the patient. Of course it is natural that parents become protective of their child when a diagnosis as serious as an ED becomes reality. In an especially interesting article in *The Globe and Mail*, a parent describes her ordeal of confronting her daughter’s ED and attempting to navigate the associated emotions that she, herself, is feeling:

Family dinners are a nightmare. She won’t eat anything other than plain fish or chicken with boiled veg. If I put any fat on it, she screams at me and doesn’t eat. I think she’s eating carrot sticks for lunch at school; I beg her to eat more. She refuses. She pretends to take the subway, but I watch, and she’s walking. She goes for a run often. Over-exercising is part of the illness. I watch, I worry, I sneak fat into meals. (Kates & Kates, 2003, p. 3)

The mother is portrayed as feeling essential to the healing process and even responsible for the deterioration of the patient. Subsequently, she is portrayed as essential for eradicating the symptoms of the ED for her daughter. “Mara, her eldest, stopped eating. It tore the family apart. ‘This is my fundamental job, to keep my child alive. And I couldn’t do it...’”(Kates & Kates, 2003, p. 3). This mother is feeling the impact of the ED taking hold of her daughter, and further views the situation as “fundamentally” her responsibility to address..

Many of the parents who share stories of their daughters succumbing to ED symptoms, describe this associated feeling of responsibility and helplessness. For example, this excerpt from the *Toronto Star*, which speaks to the experience of a mother whose daughter passed away due to lack of medical support for her ED:

It took three years to get Danielle into a program at Toronto General Hospital, her mother recalled, and there were no after-care programs. At the time of her death, Danielle weighed less than 60 pounds. Physically frail and emotionally spent after fighting the disorder for eight years, Danielle died in her parents' arms. "It was a battle then and it still is now," her mother said, adding there are thousands of parents across the province facing the same hurdles because of lack of funding for treatment and programs. (Ferenc, 2005, p. 1)

These parents logically comprehend that a physician could help, but are let down when the medical system is not set up to help their daughters. The family is essential to the process, and is fiercely supportive, but even this does not guarantee that the ED will not take the life of the patient. This points to errors in the system rather than individualistic or micro-level support systems.

The supportive and essential narrative is also supported by media reports of the family as a crucial component of effective treatment. For example in this excerpt from the *Ottawa Citizen*, a new strategy for mental health care is described:

CHEO and the Royal Ottawa Mental Health Centre announced a new strategic plan Thursday to reduce wait times for children and youth in need of mental health services. The Young Minds Partnership would also help more children under the age of 12 get into hospital beds for mental health treatment - an area of growing demand - and create a stronger system of mental health services for children, youth and their families. (Payne, 2016a, p. 2)

The fact that the system needs to be strengthened for young people and their families indicates the essential nature of parental involvement. It also emphasizes further that systems larger than the family are being scrutinized for not supporting the parents who are determined in their search

for answers and help. Those who cannot find this in existing forums, often turn to creating new options and advocating for change.

Ms. Neville knows what it's like to be a parent whose child is starving herself. She and two other parents founded Hopewell because they felt there was a lack of services in Ottawa for their children. She says it's a frustrating situation for parents, because the more they try to force their children to eat, the more determined and secretive their children become. (Heartfield, 2004, p. 1, *Ottawa Citizen*)

These parents are supportive, and attempting to make meaningful change happen for the entire demographic and are seen to be integral to the treatment process. The parent is painted as the answer to the systemic issues being highlighted. Often these mothers have created community organizations meant to improve the lives of ED patients, citing their frustration with the system as a motivating factor for their creation. This neoliberal move once again shifts the blame to the parents, to fix the structural issues of the ED treatment system.

### ***Supportive and Nonessential***

The supportive and nonessential family is described as fully supportive of the patient, and is considered nonessential to the patient's treatment and growth at this point in the process. They are supportive of decisions made by the physician for the patient, but do not play an active role in the treatment process themselves. The physicians occasionally attempt to move these parents from nonessential to essential, but as long as they are perceived to be supportive of treatment, they are largely discounted in the discourse.

Some parents identify the need for the child to separate from them in order to grow and flourish, and in this way they are nonessential to the treatment process, but are fully supportive. A mother in *The Globe and Mail* brings up a crucial point, that being a truly supportive parent sometimes means letting go and understanding that the work needs to come from the patient themselves. This is extremely interesting for the discussion of agency for young people, because

it implies that youth agency is at least somewhat dependent on a conscious shift in power from adult allies. Further, to round out the article from *The Globe and Mail*, this mother communicates that she had an image in her head of what the supportive mother should look like: “it’s a new relationship with this almost grown up. I have relinquished control over her, and with it the folly of trying to be the perfect mother. Mara is still very sweet to me. I feel so lucky - that she chose to live, and that she came home to us” (Kates & Kates, 2003, p. 4). Letting go of expectations, in the case the mother’s, resulted in a closer bond, solidifying the supportive nature of the family in this narrative of the ED impacting the entire family unit. The responsibility shifts to the patient in the statement “she chose to live” which is beautifully worded. It sums up the portrayals of multiple other parents in this section of the quadrant whose stories were featured in newspaper articles that I reviewed for the purpose of analysis.

As for the constitution of youth agency, supportive and nonessential family units are not mutually exclusive with youth empowerment. Parents often express that they want the voice of their child to be heard in the political, medical, and family structures. In another example from *The Globe and Mail*, this mother is describing how she has begun to come to terms with the responsibility of her daughter’s return from treatment, and the separation that has become a part of the treatment process.

Time to come home. I am both overjoyed and scared. What if living with us makes her sick again? I hang on tight to the metaphor of the bus terminal and work to respect her autonomy. It was her illness, it’s her recovery, not mine. It’s going well. My lesson is still about who’s in charge of her health. I have to remind myself that it’s not me. It’s getting easier to trust her as I watch her keep eating and keep the weight on. (Kates & Kates, 2003, p. 4)

The parent sees herself as so crucial to the healing process that she feels nervous that she will set off a trigger of ED symptoms just by having her daughter back in the family home after a few

months of inpatient residential treatment. While she is supportive of the need for treatment, she is ultimately nonessential in the development and growth of the patient with the ED.

Sometimes the parents relinquish the responsibility of caring for the patient at home to the hospital and the patient themselves.

Ms. AS's parents both said in evidence that, as much as they loved their daughter they were not at that time prepared to accept her back into the family home because she needed more care and treatment than they were able to offer. They wanted some prospect she could successfully reintegrate into the community before she came home. Ms. AS did not wish to remain in hospital but said she would stay until she found alternate accommodation." (*AS (Re)*, 2006, pp. 5–6)

These parents communicate that they feel ill-prepared to support the child, and therefore remove themselves from the situation as much as possible. The discourse portrays these parents as passive agents who may indeed support the need for treatment, but are not able to participate actively in the treatment process. The reader is invited to judge the parents who are lacking in power over their daughter for "not doing enough" to try to "save" the patient.

### ***Harmful and Nonessential***

The harmful and nonessential family is presented as detrimental to the wellbeing of the patient, inside and outside of treatment, and the relationship is deemed nonessential to the growth of the patient. A surrogate for the parent is then justified, often in the form of physicians and a team of professionals. This is not explicitly stated, but is alluded to when the family is broken down as harmful and removed from the situation for the benefit of the patient.

Regarding her medication, C stated that she would "have to" continue on it. She said R made her promise to take the medication. She wondered how she would be able to take the medication while living with her mother when her mother was against taking the medication proposed by Dr. Lamke. C was encouraged to make her own decisions regarding her well-being despite ongoing intense conflict between her parents. (*C (Re)*, 2009, p. 6)

The idea of voluntary status and living back with the family is usually constructed to be worse than involuntarily being in hospital away from the family. This limits the patient's agency and is an indicator that the family falls within the harmful and nonessential area of the quadrant.

Another indicator of a family perceived to be harmful is the portrayal of the family as difficult to manage within the treatment process or hospital setting. When they are deemed nonessential as well, their behaviour is used as justification for dismissing the family. For example: "Family visits have been so disruptive at hospital both to Ms. B. and other patients that they are limited to two times per week and are of 15 minutes in length" (*B (Re)*, 2005, p. 4). In this case, the patient is given limited access to the parents, but it is not constructed as a beneficial interaction.

Sometimes the disease is depicted as so pervasive that the family does not have a chance of making a meaningful impact for the child's wellbeing.

She also placed blame on her family for not providing any support with nutrition at home. However the evidence was clear that JK was rarely at home for meals. She had not fared any better staying at the Keystone Residence, where she was never present for meals or therapy. (*JK (Re)*, 2014, p. 9)

The fact that the environment is deemed unimportant to the patient's growth and development, supports the notion of the family unit as nonessential. Often these families are also portrayed as detrimental to the patient in a physical or mental manner, for example, in the above-mentioned court case, the lack of proper nutrition provided at home. The family is presented to be neglectful, but ultimately the disease trumps all actors involved.

Sometimes, in situations like this, the parents are brought in to support the perspective that the patient needs help and is powerless to the toll of the illness. For example in *JS (Re)*, 2018 the father is asked to give his opinion on his daughter's coping abilities when away from hospital:

Asked how long he thought JS's new skills and strategies might allow her to resist a suicidal urge, he replied that it could be five minutes or two hours or a week. Four months was the longest she had gone between suicide attempts... He pointed to the AWOL incident in December when she did not want to use drugs and had promised CAMH staff that she would avoid trouble, but she used drugs anyway. (p. 13)

He indicates that his daughter has relapsed before with drugs and mental illness symptoms of suicidality. The father is being asked about the newly acquired skillset of the patient, and the qualifications of the parent are not being questioned. Possibly because of their uniquely close proximity, and presumably relationship, the father's opinion is taken to be solid supporting evidence that JS should remain in hospital involuntarily. Again, the protectionist language that fuels this discourse is evident. We can see him emphasizing the various ways his daughter could be hurt again, based on past experiences with unsuccessful re-integration attempts. The hospital is a crucial component of healing in the narrative of the patient living with parents who are at their wits end. Relapse, is another way in which the parent indicates a failed attempt at recovery and their desperate hope that the hospital will help the patient heal by keeping them in the safety of the space. The family who is unable to prevent the patient from relapsing is depicted as detrimental to the process, and once again is judged for "failing".

### ***Harmful and Essential***

The harmful and essential family is described as harmful to the patient and in opposition to the treatment team. This narrative is usually utilized to exemplify the need for a surrogate decision maker via physicians or other mental health professionals. Sometimes the family is portrayed as significantly harming the patient and potentially causing the ED symptoms to emerge or flare up. For example, in the following court case, the family environment is described throughout the case as turbulent, and potentially harmful for the patient:

Her father testified that he could not keep her safe at home and JS acknowledged that she faced significant risk at a shelter but she did not appear to care. While there was some hope on JS's part that her family may take her home if there was no other option, the Panel found that *this would not decrease the risk of JS causing harm to herself. In fact the Panel concluded that living at home could increase the risk given the conflictual familial relationships and evidence of past suicide attempts at home.* (JS (Re), 2018, p. 17) [emphasis added]

In this way, the family unit has an undeniable impact on the patient's life, and therefore an alternate family unit or other support system is necessary for the patient to heal and grow.

Another way in which the family is constructed as harmful but essential is in depictions of parents as influencers of ED related behaviours such as dieting. This is much more prevalent in the newspaper articles. For example in the *Toronto Star*, an article noted that,

Environmental factors, including pressures to be thin, can trigger the underlying risk, he believes. Kaplan suggests parents who have a strong history of anorexia in their families take some preventive measures: they should avoid talking about people's weight or shape, having diet products in the house or labelling foods as either good or bad. Self-esteem, he adds, has to be kept separate from weight and appearances and even from successes at school or in sports. (Ogilvie, 2008, p. 1)

The family in this type of situation is framed as essential due to the need for the parent(s) to learn better skills in order for the patient to positively impact the wellbeing and treatment of the patient. In these situations, experts offer advice to parents to attempt to move them into the essential and supportive zone where they can contribute positively.

The relationship status of the parents is brought up quite often in court cases as evidence of a potentially tumultuous home environment that would likely be dangerous for the child to exist within. For example: "the precipitants to her illness include having a very close friend with anorexia nervosa as well as doing a school project on it. Although she nor her parents brought the issue up, they are separated and this could be a stressor" (CS (Re), 2017, p. 5). The impact of the parental separation is cited as a stressor for the patient from the Board despite the fact that it was not presented as significant by either party. It is added as a potential risk factor for the

patient to return to the family home. This indicates the unintentional harm that divorce and separation can cause for the offspring, especially when they are seeking treatment.

Parental behaviours are also scrutinized in the accounts of the family, particularly those that are traditionally deemed problematic, for example, drug use: “GB had experienced a number of traumas. Her parents had a history of drug abuse including cocaine” (*GB (Re)*, 2012, p. 3). The parents’ use of cocaine is cited as a trauma that the patient experienced prior to admission. This lack of parental concern for the wellbeing of the patient is suggested to have resulted in the development of ED symptoms as a method of coping with the loss of control. This particular case exemplifies a pattern in which the parents’ choices have an inextricable link to the child’s overall wellbeing, making them essential to the process. Readers are prompted once again to impose judgment on the parents, whose “poor decision making” resulted in the development of an ED for their daughter.

Finally, many parents throughout the board cases are highlighted due to their lack of compliance with treatment plans as prescribed by the doctor and agreed upon by the patient, presumably. In this court case, the patient voices her concerns of living at home again as a voluntary patient, and is attempting to explain her reasoning for looking for alternative housing arrangements before discharge:

She wondered how she would be able to take the medication while living with her mother when her mother was against taking the medication proposed by Dr. Lamke. C was encouraged to make her own decisions regarding her well-being despite ongoing intense conflict between her parents. (*C (Re)*, 2009, p. 6)

The doctor in this case prompts the patient to develop independence from the parents, given constant conflict in the home. They confirm the patient’s involuntary status, to keep the patient in hospital, in order to provide support that they would not receive if they were to return home. This implies that the hospital is a surrogate home, and that the treatment team is a surrogate

family. This is an extremely common pattern in the legal cases. While the parents are removed from the process, a marginal reallocation of responsibility takes place, and the patient is afforded slightly more agency. This is a surprising consequence of the forced removal of the nonessential parents from the treatment process. The patient is encouraged to begin to develop agency, and to develop a sense of responsibility for her well-being. While this is an improvement to the overall positioning of the discourse to exclude patient voices, it still only takes place due to the removal of the parent, who is preferred as a primary decision maker.

### **The Helpful Parent Spectrum**

Parents are described across platforms as the lead opinion and dominant voice in decision-making processes. The parents are generally considered a potential helpful actor in the process of diagnosing and treating patients. I have noted a spectrum in the depiction of the helpful parent. On one end, the Assistant, which is the parent who helps the physician “do their job” thereby assisting the physician in their treatment of the patient. On the other end, the Enabler, which is the parent who helps the patient “fake” wellness, enabling the “unhealthy” behaviour of the patient.



**Figure 2.**

As with the Support Quadrant, parents may move around on the spectrum throughout the process, based on their described actions. However, there is no consensus on the parents’ rightful place along this spectrum. Various perspectives on autonomy and protection converge to create differing goals for the parents’ positioning. For example, a child and youth advocate may argue

that the full agency and autonomy lies in the hands of the patient, and therefore the parents should act as strong allies by supporting the patient on the enabling end of the spectrum. On the other hand, a physician on the front line may advocate that the child's best interests are prioritized when the parent assists the physicians with their assigned treatment plan. I will now elaborate on what each category entails.

### *The Assistant*

The parent who is portrayed as helpful in court cases from the perspective of the court is often supporting the objectives of the physician in treating the patient, no matter what it takes. The ultimate objective of this type of parent is for the physician to cure the patient of their illness, and take away the big picture pain, regardless of the approach utilized. Comparable to the concept of the ends justifying the means, the parents in this category are totally behind the physician's decisions. Another way this parent is conceptualized is the risk-averse parent. Anything that seems as if it could jeopardize progress or safety of the patient, is dismissed by the parent as an unwise choice regardless of the perspective of the patient. Discursively, this type of parent empowers the experts by unconditionally supporting the actions of the physicians.

Oftentimes this type of parent is presented as directly contradicting the patient, with their account of how events played out. This operates in court cases to show the illogical thought process of the patient, disempowering them.

Ms. B. reported she ate two granola bars, a peanut butter sandwich and pumpkin pie while at home. *Her mother reported to Ms. Leahy, she only nibbled.* (p.4) Ms. Leahy, Mr. Foulon and Ms. Foster's evidence all indicated that *this individual required constant supervision to make decisions* as to her needed dietary and also to ensure her taking her nourishment. Until shortly before the hearing, despite her intelligence and constant dietary and health teaching, she was unable to make dietary choices and even the day before the hearing, failed to include one aspect while being supervised. On an elopement the day before the hearing, *she reported eating several items, which if eaten as reported potentially would result in refeeding syndrome.* *Her mother reported to staff a quite different eating pattern while out of hospital.* (B (Re), 2005, p. 8) [emphasis added]

The mother's testimony indicated the child was manipulating the story to make it seem like she was eating more. While this may well be the case, this is a prime example of the mother being framed as siding with the physician in order to preserve the status of the treatment and attempt to keep her daughter safe in the best way she knows how. Further, parents in this position are often portrayed to be surveilling the patient on behalf of the physician. "DK, her father, said in his evidence that in the car coming home from London Hospital, JK declared that she had no intention of adhering to the follow-up plan set out for her" (*JK (Re)*, 2014, p. 10). This father is reporting on private interactions with his daughter that contradict her statements of commitment to treatment. Further, these parents often serve as discursive confirmation that the patient is in desperate need of support. In many cases the parents testify that they agreed with the physicians in the treatment, and signed off treatment to the experts to attempt to treat their daughter:

The uncontradicted opinion of Dr. Abramson was that OP was suffering from anorexia nervosa. The opinion was supported by Dr. Riggan, who was part of OP's treatment team. As noted, this was OP's third admission to hospital since November 2016. *Background information from OP's family adequately corroborated the doctor's opinion.* Exhibits 2 and 3, both of which were emails from OP's mother, set forth detailed narratives related to OP's refusal to eat and the consequent stress this occasioned to the family dynamic. OP admitted she suffered from an eating disorder, but stated she didn't "think it was as bad as everyone is claiming. (*OP (Re)*, 2017, p. 5) [emphasis added]

It is interesting that the word "corroborated" is used here. It implies that the physician's opinion in combination with the parents' opinion is solid evidence that the opinion of the patient is incorrect. This has a major impact on the determination and framing of involuntary status.

Parents are often cited in ED literature as among the first to recognize troublesome symptoms in young people (Sibeoni et al., 2017; Ungar, 2004) and as discussed earlier, parents are often the target audience of news media mobilizing affect for change. The parents in court cases are constructed in the same way, as a front-line defence against the eating disorder itself:

By March 2017, CS's parents noticed that she had significantly decreased food intake. She began eating almost exclusively fruits and vegetable, and stated to her mother that she would have an maximum kilocalorie intake of 500 daily... In March 2017, CS's mother took her to the family physician's office for a weight check and requested a referral to an eating disorders clinic. (*CS (Re)*, 2017, p. 4)

The parents are shown as advocates for treatment, and the first to notice the early signs of EDs.

In newspaper articles, this type of parent follows a narrative of one who does everything they can to combat the difficult to navigate system. In an article in the *Toronto Star*, the lack of funding is constructed as the main reason why the number of EDs continues to rise in young women and girls:

Without semi-private coverage, the cost is \$222 a day. For the program's lone ward bed, fully covered by OHIP, the wait would be up to two years, Sterenberg was told. The family had 48 hours to make a decision. Sterenberg was told no provincial money was available for the Homewood room but the province would pay for treatment in U.S. facilities if a delay would result in death or irreversible tissue damage. Sterenberg wrote to government officials, including Premier Dalton McGuinty and Ontario Health Minister George Smitherman, asking for financial assistance. They wrote back detailing increased funding that had been provided for eating disorder treatment in Ontario. With no help available, Sterenberg and her ex-husband managed to scrape together the money for Amanda's treatment through a combination of savings and loans. "She is progressing slowly," her mother says. When she is discharged in May, "she'll be at a healthy weight, but she won't be fixed. It could be a lifelong struggle." Early treatment is critical, says Kathryn Barratt, executive director of the Eating Disorders Awareness Coalition of Waterloo Region. "There are a lot of people who need in-patient care and they just can't get it," Barratt says. "People are dying because they didn't get the treatment they needed." (Kelly, 2008, p. 3)

The parents in this situation are depicted as at the end of their ropes, and attempting to lean on public resources to treat their daughter. They are allies with the physicians in that they support the need to increase funding and are fiercely advocating for change. The interesting thing is that the patient with the eating disorder is rarely interviewed in newspaper articles<sup>8</sup>, but rather the

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<sup>8</sup> I'd like to acknowledge that there are in fact good reasons for not interviewing patients, particularly young people, including not being bothersome for the patient and their family during trying times. Ethically, it can be questionable to interview a member of a vulnerable population directly. However, the fact still stands that there are significantly low numbers of young people featured in news media, which matters regardless of intention.

focus is on the parent who is unable to get help for their child. These parents are classified as Assistants because they dominate the news media discourse for the sake of the bigger picture as they call for more access to treatment and more funding for mental health services.

### *The Enabler*

The parent who helps the patient is often portrayed in the cases to be supporting the patient in deceiving the physician. This parent is painted as reckless and difficult in the treatment process, countering the treatment team at every turn. This parent is cast as short-sighted, in favour of short term gratification for themselves and the patient, rather than committed to big picture treatment goals. Interestingly, there is no equivalent of this type of parent in the newspaper articles. The parents are located in a sympathetic narrative in the news. This is likely due to the fact that parents are the targeted demographic reading newspapers, and appealing to their sense of responsibility long term is the goal of newspaper articles.

In many court cases, the increased use of adjectives is used to emphasize how outrageous it is that the parents took the side of the patient. For example:

*L and her parents talked repeatedly of discharging her from hospital despite her malnourished and medically unstable state. The treatment team also reported that on many occasions, L's parents, pressured by her, acted against the treatment plan (e.g. by requesting that the PW be lowered, making inappropriate comments regarding food, and hiding food). Towards the end of the first admission, L and her parents advocated for her discharge before reaching the weight recommended by the treatment team (90% of PW). At their insistence, she was discharged against medical advice at 86% PW after three months in hospital. (L (Re), 2009, p. 4) [emphasis added]*

The parents are depicted to be illogical in this excerpt, by positioning the medical team's perspective alongside that of the parent that is pushing for the patient's requests to be fulfilled. However, the emphasis is sometimes placed in questionable places to highlight parental incompetency. For example, saying that they took her out against medical advice indicates that

they are bad parents, whereas saying that the parents took her home at her request to help her re-integrate, slightly before the medically advised PW had been reached, may have been more accurate given that she was only 4% away from the goal PW. This is just one way in which the perspective of the Board, reviewing the case, comes through and demonstrates the inclination to privilege experts over parents, especially those who disagree with the physicians. Complete obedience to the legal framework, it seems, is required.

Medication is an area of contention for parents and physicians in the representations. Often, the parent who does not support the use of medication for ED symptoms is depicted as irrational. For example:

S [mother] does not agree that a past trial of lithium has been helpful to C, even though the lithium allowed C to return to school successfully. With C living at home with her S would only go as far as leaving C's medication in a back-pack in the living room. S never encouraged C to take her medication. Despite overwhelming medical evidence and at least 5 similar diagnoses, S's position on C's treatment has never wavered. She has an intractable inability to take into account the symptoms of her daughter's illness. (*CS (Re)*, 2017, pp. 6&7)

The parent is portrayed as an irrational actor here, through highlighting that the medication made her daughter feel well enough to return to school and emphasizing her continued rejection of medication. These parents are also represented as detrimental to the child's treatment. The lack of supervision the child receives at home, when it comes to medications, reinforces the position that the patient is safer in hospital where their medication regimen can be monitored closely by experts. In *C (Re)*, 2009, the patient is described as illogically rejecting medications, and the Board says that the medical team enforced medication by threatening her mother: "S has always been against medication and only agreed to it under duress and the threat of the involvement of Children's Aid Society (CAS) prior to C turning 16" (*C (Re)*, 2009, p. 7). In this case, the mother agreed with the patient that medications were too invasive for the level of progress that her

daughter had made. The fact that the team then threatened to call protective services on the mother – despite both parties agreeing about medication use – shows the structural power dynamic between physician and parent.

In some cases, parents are involved in the deceit of the medical team in efforts to remove their child from the hospital on the grounds of wellness. An example of this is found in the following excerpt:

It was reported that L and her parents were disrupting the treatment plan, including an incident where L was found trying to artificially inflate her weight with a D battery and two pairs of underwear. L was assessed and again found incapable to consent to treatment of her ED, with her parents as [Surrogate Decision Makers]. (*L (Re)*, 2009, p. 5)

The parents – who believe they are helping their daughter by doing anything they can to get them out of hospital – are portrayed as having a short-sighted belief that the current comfort outweighs the long-term wellness. These parents are often evaluated in terms of their capacity to be SDMs<sup>9</sup> in the case of their child, assuming the child is still involuntarily committed:

The treatment team was concerned about the ability of L's parents to act in her best interests as SDMs. Accordingly, they had asked the Office of the Public Guardian and Trustee to investigate and to consider assuming temporary guardianship of L. This matter was outstanding as at the date of our hearing. (*L (Re)*, 2009, p. 5)

A parent who desperately fights for their child by deceiving the treatment team may not be considered suitable SDMs, given their seeming inability to comprehend the seriousness of the disease.

This parent is living out the narrative of misguided love and care. Their relentless push for wellness in the face of overwhelming difficulty is not depicted well. In the legal cases, the

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<sup>9</sup> Surrogate Decision Makers (SDM) are officially designated decision makers, under the Ontario Mental Health Act, that act in the best interest of the patient when they are deemed incapable of understanding the complexities of their decisions in relation to the illness from which they suffer. In the case of young people, this is almost always the parents.

Board is disciplining the family and instructing parents in how to be a “proper” parent of an ED patient. They do this by highlighting the many ways that these parents have failed. In some ways, the court treats parents as a surrogate for disciplining the patient. It would be clearly inappropriate to discipline a patient for having an ED, as they have no agency over the situation. The prospect of condemning parents is not off-limits, because the implication is that they have control and power over the development of EDs.

The family is constructed in many ways to be responsible for the growth, or lack thereof, of the patient. In many ways, the parents are relied upon for information, when it matches the opinion of the experts. However, they are also quickly discredited when their efforts are deemed harmful, when they attempt to (misguidedly) demonstrate love and support for their child through enabling behaviours and deceptive actions in hospital. The family is crucial to the construction of the patient as vulnerable, and plays a role in the empowerment of the child when their voice is removed from the conversation.

## Chapter 5

### The Patient as a Broken Child

*“She is progressing slowly,” her mother says. When she is discharged in May, “she’ll be at a healthy weight, but she won’t be fixed. It could be a lifelong struggle.”*  
(Kelly, 2008, p. 3, Toronto Star)

In Western culture more broadly, the child is constructed as vulnerable by default because of their age, and children with EDs are further constructed to be vulnerable due to their perceived fragility and irrationality associated with the illness (Gilligan, 2009). The “Broken Child” emerges as a central theme that runs throughout the discourse across all three sites I examined. I define this concept as the child in need of ‘fixing’ after being damaged by the ED. The ED is constructed as a force that cannot be overcome and ultimately takes over the (always) vulnerable child. This theme encompasses the patient prior to the onset of the disorder, during the disorder, and post-treatment (if applicable). There are contradictory messages about what it means to be a child that emerge in viewing the patient as broken in the first place. The assumption is that the child is a fully formed person that can in fact be broken, and further that the ED is a problem that can, in fact, be fixed. In contrast, there is a constant depiction of the child as evolving and growing into a fully formed person, currently deemed intellectually incapable of logical decision making. These are discussed in the following sub-themes.

#### Happy and Healthy vs. Volatile and Fragile

The narrative of the child, in news articles and in the court cases is one of the happy and healthy child who transforms into the sick child. The child who has been diagnosed with an ED is suddenly volatile and fragile. The child is portrayed as naturally friendly, but currently

exhibiting aggressive or irrational behaviour, and as someone who could cause harm to themselves or others involved in the situation, such as parents or physicians.

The happy and healthy child is constructed as an overachiever, and all-around good citizen. There is often a lengthy description of the patient as lovely and smart, as well as very involved in school or work activities, and part of a strong family dynamic. This is exemplified in the following illustrative excerpt from the *Ottawa Citizen*: “Parents Jason and Kerry McRae say Jenna was a brilliant student in both the sciences and arts, and was offered a mathematics scholarship from Carleton University in late 2013” (Adami, 2015, p. 1). These factors are meant to build a picture of a young person who is presentable, healthy, and happy. In contrast, usually immediately following the idyllic description of the young person is a description of their current state post-ED diagnosis.

After the above mentioned quote, the article continues: “‘She could be so much,’ says Jason. Jenna would have now been in her first year, but near the end of her first semester of Grade 12, the relapse forced her to drop out” (Adami, 2015, p. 1). The follow up descriptions generally give a much more negative picture of the patient using descriptors that paint a specific picture of the volatile and/or fragile young person. These depictions in the news media discussion of EDs of young people provide an agreeable and pleasant young person, who could not help but succumb to the disease.

Katherine Duff is 16. She comes from a close-knit Toronto family. She has a part-time job and gets straight As. She loves poetry, watching movies with her younger sister, and going out with friends for dinner or to the mall. She adores animals, especially dogs. And she wants desperately to go to university and become a lawyer. Like her dad. (MacDonald, 2013, p. 1, *The Globe and Mail*)

The article goes on:

But for two years, Katherine was locked in a downward spiral of angry, self-destructive thoughts. She heard voices. She cut herself (she has multiple scars on her arms and legs).

Diagnosed as bipolar with borderline personality disorder (BPD)<sup>10</sup>, she tried twice in the past year to take her own life, both times overdosing on Seroquel, one of six anti-psychotic drugs she takes to regulate violent mood swings. On good days - which for a while were rare - she went to school, worked at a doggy daycare, and baked cupcakes with her mom. On bad days, she shut herself off from society, curled up in bed weeping. (MacDonald, 2013, p. 1)

It is so interesting that the dichotomy of good and bad is so explicit. This is not an isolated example; many newspapers and court cases follow this exact narrative format, in which they begin to soften the reader prior to the harsh reality of an ED.

This pattern almost mimics traditional depictions of growing into adolescence from childhood. Adolescence is typically represented as a time of turmoil and destructive behaviour, following childhood which is typically represented as a time of innocence and wonder (James & Prout, 2003; Shuttleworth, 2013). An example of this pattern in the court cases is found below:

WZ was a 17-year-old, grade 12 student. She lived with her parents and was a very successful in school, having obtained high grades. On October 20, 2010, WZ attended the Adolescent Eating Disorder Clinic at NYGH. WZ had been referred for the assessment by her family doctor, based on concerns that WZ was very under-weight. WZ was assessed by Dr. Leonard and found to have a number of serious medical complications secondary to malnutrition. Dr. Leonard also had concerns about WZ's capacity to make decisions about her treatment and determined that WZ was incapable. (*WZ (Re)*, 2010)

In the introduction to this patient, we learn that WZ is considered a bright, high achieving teen, who has obtained high grades. Immediately after, we hear that she was deemed incapable of understanding the consequences of her symptoms on her health without adequate support. It is interesting that the girl is depicted as smart prior to the admission, and then suddenly unable to understand the situation once she is diagnosed. This phenomenon is analyzed further in the next section.

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<sup>10</sup> This particular child had multiple diagnoses with BPD being one of three, including a severe eating disorder.

## Conditional Intelligence

Intelligence<sup>11</sup> emerged as a significant sign in the discourse in relation to patient capacity. Certain conditions must be met in order to gain the title of intelligent in the eyes of the court and/or the general public. I have labelled this discursive trope, ‘conditional intelligence.’ In this frame, the patient is granted the possibility of being intelligent; however they are not currently able to access this due to the circumstances in which they find themselves. Intelligence essentially functions as a proxy for capacity and hence legal agency in court cases.

I have noted three conditions in the discourse that must be met in order to demonstrate intelligence. First, “the subjective acceptance of the ED as understanding EDs.” To meet this condition, the patient must be willing and able to understand that they have been medically diagnosed with a serious ED. The second condition is: “hospital as an ideal place of healing.” In this, the patient must view the ED as treatable, and support the use of medications to achieve total abstinence of symptoms, free from relapse. Finally, condition three, “capacity as compliance,” in which the patient must inherently trust experts in the field and not disagree with the prescribed approach.

Patients are able to exhibit partial intelligence by fitting one or more (but not all) of the conditions of intelligence. They are often highlighted as extremely bright in one way, but failing in other aspects of their intelligence. The elements of the intelligence are built around each individual young person, but follow the aforementioned patterns fairly consistently across the

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<sup>11</sup> It is worth noting that the term intelligence was not defined by any of the cases, but rather left open to interpretation. Emotional intelligence is related to the will to stay alive and get healthy, and is almost always separate from regular intelligence which is conditional upon logical thinking skills. The intelligence of the patient is clearly a matter of importance to the Board and the public, given the amount of times it emerged across the discourse. This makes it even more interesting that there is no solid definition of what this means.

discourse. Interestingly, it is not always considered positive to gain the title of intelligence. For example, in the following excerpt from a legal case, the patient's drive and intelligence are used against her in the reasoning of confirming her incapacity: "LC's disease is such that we are convinced that she is so anxious, so much in the moment and *so driven* that she would most likely behave in exactly the same manner on each similar occasion in the future" (*LC (Re)*, 2002, p. 3) [emphasis added]. Despite the statement that this is a young woman who is described previously as having done research in the area of ED treatment prior to attending the trial, LC was ultimately confirmed to be incapable of making decisions by the board. Patient intelligence in these types of court cases is not a protective factor for the patient. In situations like this, patient intelligence is deemed to be a *risk factor* for recidivism, or even the original onset of the ED, as shown here in the following quote from the *Ottawa Citizen*: "it's the good girls, the achievers, Ms. Neville says, who are often vulnerable to EDs. The pleasers" (Heartfield, 2004, p. 2). This depiction of intelligence as a risk factor is extremely common among the newspaper articles, and actually was uncovered in my literature review (Cullen, 2010; Dr. Clare Roscoe, n.d.; Fisher et al., 1995).

Even when a patient manages to meet all of the conditions, there is usually a reason found to confirm incapacity and involuntary status:

Essentially L's evidence was to the effect that now that she had attained 100% of PW, she could manage the rest of her recovery (what little was remaining) as an outpatient, and no longer needed the structure of the type of treatment being proposed by the team at HSC. She conceded that she had been incapable while she was underweight, but believed she had regained capacity when she achieved her PW. She suggested that everything has changed when she achieved her PW, and although she had previously been in the grip of the illness, that was no longer the case. While she also said things like "I know there is no guarantee I will recover" and "my ED is very serious", we found those parts of her evidence to be scripted and rehearsed and inconsistent with the rest of the evidence. (*L (Re)*, 2009, p. 10)

This patient hits all of the conditions and requirements, but the Board states that she was “scripted” in her responses, and therefore overrides the previously mentioned intelligence. Thus, intelligence remains, within popular and legal discourse, an unattainable goal or a Janus-faced achievement for the intelligent patient with an ED.

***Condition one: Subjective Acceptance of ED as Understanding EDs***

For this condition to be satisfied, the patient must accept that they have a serious ED, or produce a convincing performance of acceptance. This acceptance is subsequently equated with having an understanding of EDs. If the patient does not agree that their symptoms are the result of an ED, they do not satisfy the requirements of this condition. There is a narrative structure that shapes almost every legal case, in which the child is presented as understanding what the ED is ‘objectively,’ but unable to “subjectively” understand (i.e. apply this definition to themselves).

In this testimony given by the attending physician on her case, the patient is directly addressed:

It is my assessment that your fear of weight gain is intense and delusional in nature. It is much more than a lifestyle choice and you are unable to appreciate and control its effect. While you are extremely articulate, bright and developed a good understanding in general of EDs and possible complications, you are having trouble appreciating the effect of your thought disorder and actual choices of your health. (*JK (Re)*, 2014, p. 6)

JK’s objective understanding is emphasized to be good, but not enough to show that she is capable of comprehending the impact of her choices in regards to her own wellbeing. This is quite common among court cases as a justification for maintaining involuntary status of the patient.

The narrative of the morphing child begins with complimenting the patient’s abilities, then contrasting it with the way in which the ED has influenced these abilities. This general format is followed in almost every case. The Board almost always starts by acknowledging the

intelligence of the patient and then proceeds to explain why, despite, or even because of, this intelligence, they are upholding the judgment of incapacity.

Ms. AS *was* a very bright, engaging and personable young woman. She clearly had an intellectual understanding of her diagnosis and the potential consequences of not complying with treatment. She also had a clear plan to improve her chances in the community... Ms. AS also recognized that illness frequently ‘did the talking,’ as when the week before the Hearing, she challenged Dr. Couturier’s assertion that she would have to remain in hospital until she weighed at least 47.7 kg. *Ms AS’s problem was that her illness did too much talking.* It controlled her decisions about food intake. If not on an intellectual level then on an emotional level, Ms AS *could not believe* that she needed to weigh as much as her treatment team and parents urged. She believed she would be healthy at 47.7 kg and without risk if she weighed 85 per cent of that. (*AS (Re)*, 2006, p. 8) [emphasis added]

In indicating that the patient’s illness interferes with her ability to deduce that she must gain weight to improve her health, the intelligence of the patient is put in the past tense. Something that is still a part of the individual, but not currently accessible; her intelligence is referred to as a previous trait, not one that she currently holds.

### ***Condition two: Hospital as an Ideal Place of Healing***

In order to satisfy condition two, the patient must demonstrate that they believe their eating disorder is medically treatable (with medication) within the hospital setting. If the patient leaves the hospital and relapses this is used to justify keeping the patient in hospital involuntarily. Given that relapse is constructed as a complete failure to thrive on the part of the patient, this is to be avoided at all costs.

The departure from the hospital is associated with these relapses across newspaper articles and court cases. The following instance is from *B (Re)*, 2005 (p. 8) and exemplifies the emphasis that is placed on the physical location and environment in which the child is placed.

Given her state, *should she return home as of the hearing*, without treatment of her mental disorder, *she will not be able to maintain a strict balanced diet she requires in her most vulnerable state*, will potentially binge on certain foods and *place herself at great risk of irreparable physical harm or death.* [emphasis added]

Space is being depicted as incredibly important to the relapse emergence and the occurrence of ED symptoms. Risk of harm is the main consequence to be avoided, and the discourse emphasizes that without intervention these patients are at constant risk of harm and/or death.

Utilizing medical statistics that are often not cited in the material itself, the cases and newspapers emphasize the imminent risk that patients with EDs face when outside of the hospital. For example, in *BF (Re)*, 2005 the board cites the following as evidence for the incapacity of the patient:

Dr. Pinhas explained this disorder needed to be treated early if success was to be achieved. Failure often manifested itself in a high mortality rate of 10% to 20%. The severity of Ms. F's disorder was exemplified by the fact she returned to hospital in about four weeks after her discharge in November. Though relapses do occur in certain patients, such usually did not occur for several months. (p. 7)

The disorder is depicted as severe and the patient as unable to resist the temptations of the real world without support provided in hospital. This is characterized as the only space in which the child is safe, and will continue to live. Further her relapse is framed as normal, but also abnormal because it happened "too soon". This is interesting because there is no specified relapse time-frame provided by any doctors in any of the cases that I read, nor has it been suggested that there is an accepted standard against which this patient should be compared. The implication is that this patient relapsed faster than most would, and therefore is still under the spell of ED symptoms.

Relapse is constructed as synonymous with failure in newspaper articles, court cases, and legislative documents, alike. Policies that regulate mental health treatment are set up to emphasize that relapsing is a major problem, and can in fact be grounds for detaining a patient involuntarily. As per the *Ontario Mental Health Act*:

- (1.1) The attending physician shall complete a certificate of involuntary admission, a certificate of renewal or a certificate of continuation if, after examining the patient, he or she is of the opinion that the patient,
- (a) has previously received treatment for mental disorder of an ongoing or recurring nature that, when not treated, is of a nature or quality that likely will result in serious bodily harm to the person or to another person or substantial mental or physical deterioration of the person or serious physical impairment of the person;
  - (b) has shown clinical improvement as a result of the treatment;
  - (c) is suffering from the same mental disorder as the one for which he or she previously received treatment or from a mental disorder that is similar to the previous one;
  - (d) given the person's history of mental disorder and current mental or physical condition, is likely to cause serious bodily harm to himself or herself or to another person or is likely to suffer substantial mental or physical deterioration or serious physical impairment (MHA, 1990, p. 8)<sup>12</sup>

Constructing past success as evidence of possible future failure is contradictory to the goal of recovery for patients which is reliant on increasing levels of success, and often based on expected episodes of reverting to old behaviours (Carey, 1996).

Sometimes, relapses or recurring symptoms are even described as intentional and aggressive, despite the fact that the consistent thread throughout is that the ED has consumed the young person and rid them of their ability to logically make decisions in regard to their own care.

She was treated for months, first as an in-patient, then in a day program, though she did not “graduate” from the latter because of transgressions such as suicidal thoughts and cutting herself with a sharp object. “It’s a way of dealing with the weight gain they forced on me,” she says. (Adami, 2015, p. 2) [emphasis added]

The fact that suicidal *thoughts* are described as a transgression is quite interesting, as transgression implies a negative action committed. This type of description supports the perspective that the relapse indicates future harm to the patient if released. Once again the

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<sup>12</sup> In the Mental Health Act under Conditions for Involuntary Admissions.

association between the ED symptoms and death is highlighted. It is also worth noting that the self-harming behaviour is described as “cutting herself with a sharp object.” The “sharp object” language was gratuitous, and may have been added for more dramatic effect, given its specificity. Even momentary relapses are considered devastating failures and evidence of incapacity for patients. It is unreasonable to expect a 100% elimination of the disorder, given the expected lengthy recovery period of months to years, with no complete cure available (Cullen, 2010). The disease and its “cure” are idealized in the discourse.

While legal discussion tends to use relapse as evidence of individual failures, newspaper articles utilize relapse to show the many times hospitals have failed patients who need treatment. For example, in the *National Post*:

Over the years, Gordon’s daughter was constantly checked in and out of ED programs offered by the Toronto General and Credit Valley hospitals. At most she was out of the program for six months before having to be readmitted. “It is the No. 1 mental health killer in young people,” Gordon says. “There’s just so many people with the disease and so little beds.” Indeed, in the Greater Toronto Area, there are only two ED programs available. (“Breaking through stigma in the battle for better eating disorders care in Canada,” 2012, p. 1)

The emphasis is clear, that the GTA does not have adequate mental health support available for young people and the consequences are fatal. It points to a structural flaw in the hospital system, failure to thrive on the part of the hospital, and failure to provide the means to thrive on the part of provincial and federal governments.

If the patient wishes to leave the hospital at which they are currently being treated, regardless of motivation, they are interpreted as incapable of understanding the value of the hospital setting in which they are expected to thrive.

The Panel was unanimous in determining that JQ is not suitable for voluntary status as she would likely demand to leave the hospital if made voluntary. This in turn would put her at risk of serious physical impairment. Dr. Couturier believes that JQ does not want to be in

hospital as she does not believe that she is at risk and minimizes the effect of her refusal to eat and in so doing is depriving herself of adequate nutrition. (*JQ (Re)*, 2011, p. 12)

Simply put, nobody likes to be in the hospital. It is generally accepted that going to the hospital can be equated with some sort of negative incident resulting in the need for intensive care.

Therefore it is unreasonable to use the urge to leave hospital in cases like the one above as grounds for incapacity or irrational thinking. Yet it emerges as a commonly relied upon reason in court cases to do just that.

### ***Condition three: Capacity as Compliance***

This condition is ambiguous and difficult to demonstrate, but it is important to recognize. The expectation for the patient is that they will make informed decisions about their treatment, based on the information provided by physicians. Board officials always begin their analysis with an introductory statement about capacity and compliance as two separate concepts. However, the implications of their decisions and language use point to an understanding of capacity *as* compliance. Further, the best interests standard is considered to be an unethical determinant of capacity that cannot be relied upon in the decision-making process of the hearing.

In almost every case the same narrative structure is used in the introduction to state that the Board is not considering the best interests of the child as paramount:

The Court noted that the right to make one's own treatment decisions is a fundamental one that can only be displaced where it is established that a person lacks mental capacity to do so. The patient's "best interests" are not a consideration in determining the question of capacity to consent to treatment. Capable people have the right to take risks and to make mistakes. Further, the presence of mental disorder should never be equated with a lack of capacity.

Despite repeatedly saying that the court was not going to rely on the principle of the best interests of the child in order to determine status of capacity, and despite indicating that compliance does not equal capacity, the discourse reveals the court reasoning for upholding involuntary status relies heavily on these very things. (*C (Re)*, 2009, p. 8)

Evidence provided in the cases almost always includes a detailed description of the patient's lack of compliance with treatment. This is often used as a way to show that the young person is not capable of applying the consequences of not receiving treatment to their situation. In *LC (Re)*, 2002 the Board explains:

LC is doing things that she knows and accepts that she should not be doing and she is refraining from doing things that she knows and accepts that she should be doing. Clearly, then, she is demonstrating that she is not able to functionally and emotionally appreciate what she intellectually knows to be the case. The problem here is not that LC is not doing what her doctors want (for that would not be an indication of incapacity) but, rather, that she is not doing what she wants. (p. 13)

The beginning of the statement emphasizes that LC has an understanding of her actions, so much so that she is doing things she “should not be doing.” This statement positions the patient as capable of understanding consequences and acting in a way that will produce specific outcomes they presumably desire. Then it is remarked that the patient is unable to appreciate the implications of her actions, which directly contradicts having an intention to act in a particular way.

Further, the statement that “she is not doing what *she* wants” is incredibly interesting because it implies that the Board is attempting to regulate the thoughts of the patient. The patient is also positioned as a person with incredible decision making power in that they are treated as a danger to themselves despite exhibiting ED symptoms that are constantly described to be skewing patients' sense of self and logical reasoning abilities. This contradiction is particularly interesting when paired with the discussion of best interests in court cases. While the Board very

explicitly states that they will not infringe on the right of the patient to make “undesirable” choices, they immediately find a rather precarious reason for infringing upon this right.

The following quote is striking, as it states that the treatment professional is *willing* to continue treatment, if the young person “co-operates” with the plan as the team has constructed.

On the 22nd Ms. F’s mother stated her daughter had reduced her intake by one can of resource; however, Ms. F. appeared to have gained a little weight and the health practitioner was prepared to continue the treatment plan so long as the patient co-operated in it. (*BF (Re)*, 2005, p. 5)

What we can glean from this type of talk about treatment is that complying with prescribed treatment is viewed as necessary for success. Any disagreement on the part of the patient is deemed inappropriate and supports claims of irrationality and incapability.

The earlier theme of the value of expertise emerges again here, in a slightly different way. The fact that the patient has the audacity to challenge a medical expert in regards to their mental and physical health is brought into the hearing as evidence of the patient’s inability to see the consequences of not complying with treatment. Real concerns about the hospital setting, food allergies, and other relevant issues related to quality of life and comfort are brushed aside as frivolous and irrelevant concerns when the patient raises these issues.

*JQ in an effort to justify her behaviour in not eating properly* raised a number of objections including the fact that the food was not measured as it was at the hospital where she was previously admitted; that she would prefer food from the outside; that she wants her food to be wrapped so that no one can touch it; that she has allergies to the food she is being served; and that nurses are spitting in her food. The Panel was not persuaded that any of these reasons for not eating are valid and that they are merely an effort by JQ to justify her refusal to consume the appropriate level of calories to maintain adequate weight and medical status. (*JQ (Re)*, 2011, p. 12) [emphasis added]

The concerns that JQ lists are not irrational or unreasonable requests in any other context, but here are meant to convey the many ways in which the patient is attempting to maintain ED

symptoms. Also, the fact that the patient is bearing the responsibility of proof here is in direct contradiction with protocol outlined at the beginning of every case.

The onus is always on the attending physician at a Board hearing to prove the case. The case must be proved on a balance of probabilities. In order for the Board to find in favour of the attending physician, it must hear cogent and compelling evidence in support of the physician's case. The patient before the Board does not have to prove anything; the onus is entirely on the attending physician. (*CP (Re)*, 2017)

With this very clear statement made in every case, it is surprising to see so much discussion surrounding the patient's inability to demonstrate their capabilities or justify their decisions in the treatment context.

If the patient is presumed to be competent until proven otherwise, then why are they consistently punished for not being able to convince the Board that they are in fact intelligent, competent, and capable? Perhaps this is an indicator that while the official policy outlined in the *Ontario Mental Health Act* is to presume competency, it is not being applied to youth cases in the intended fashion. I am reminded of the ways in which girls and women have been assumed to be irrational in political and social forums across history, and the oppressive nature of many systems that directly impact them. Especially given that the demographics of the patients in the court cases show that 100% of the patients in the courtroom attempting to have their voices respected in regards to their bodily autonomy, are female<sup>1314</sup>.

### **The Self as Constant and the Child as Evolving Conflict**

Throughout the discourse, there is a constructed child that appears across platforms, one that embodies a set of contradictions. There is a lot of emphasis on the child as high functioning

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<sup>13</sup> See Appendix 1, Demographics of Cases

<sup>14</sup> While this pattern and similarity is noted, it is beyond the scope of the current project to do a deep gender based analysis. It would be excellent for future research in the area of ED capacity.

with personality traits that indicate a solidified sense of self. However, there is also a prominent discussion of the child as an illogical and irrational being, who is in the process of evolving into a fully formed person. It is interesting that the child is expected to be both evolving as a person and to maintain a personality that is constant and logical. The concept of childhood as a state of ‘almost’ personhood, or a state of becoming, is prominent in child studies discourses (Worth, 2009). It emerges strongly in the newspaper articles and court cases analyzed for this project.

One way in which this conflict is shown is through descriptions of the patient’s recent changes in hobbies or interests. This is meant to demonstrate the patient’s instability, despite the naturally occurring pruning process<sup>15</sup> that adolescents are expected to endure. In this example, the Board describes a negative reaction that the child has had when exposed to a family activity:

All attempts by parents recently to engage her in activities have been met with resistance. As an example, a recent attempt by her mother to try and reintroduce an activity [Ms.H] previously enjoyed (an overnight camping trip) resulted in [Ms.H] being confined to the tent, and when she did (briefly) to attempt a swim she became completely overwhelmed, disorganized (scribbling jargon onto a piece of paper that made no sense), and unable to follow through given irrational fears associated with the water. (*HW (Re)*, 2005, p. 5)

The patient is described as ‘resisting’ family oriented activities with anxiety and other mental health reactions which are presumably beyond her control. This is meant to show the instability of HW. However the perception that she is unstable rests on the interpretation of events. For example an irrational fear for the person relaying the anecdote may in fact be logical for HW, but there is no room for interpretation in favour of the young person here.

Many times, behaviours that are often attributed to being a typical developing person such as mood-swings and disorganized thinking are amplified and constructed as rendering the

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<sup>15</sup> During adolescence, the brain experiences a pruning of synapses that is used to explain the risk taking behaviour and experimentation seen during this developmental period. (Casey, Getz, & Galvan, 2008)

subject irrational or unstable in anecdotes and stories of the patient's behaviour. In this case, the Board considers the possible consequences of the patient refusing treatment:

Parents describe this teenage girl as not being able to organize herself or be able to initiate a task, ie they express concern about her ability to care for herself. They say that recently she cannot cook or work or do schoolwork or housework or basic hygiene (in contrast to the lovely, bright, talented, accomplished competent girl she was up until grade 8). (*AA (Re)*, 2015, p. 10)

Ultimately, the Board determines that the patient's unhygienic tendencies are too extreme to be considered rational. However, there is no framing of the discussion of adolescent development in relation to these types of behaviours. This makes it difficult to make the leap that is too often made – that these behaviours are indicative of an incompetent person.

Another example is found in the following case, in which the patient describes feeling confused about the medicalization of what she feels are 'normal teenage' behaviours.

In her testimony, SB advised she had never experienced organ failure or fainted or faced any emergency because of her health. Ms. Jarvis reviewed some of the evidence in Exhibit 1 with SB. SB stated the record was of "limited accuracy". For example, when asked about being unstable necessitating transfer back to HSC, SB stated that the medical staff were wrong. In her statement, SB wrote: "I feel as though I am not a safety risk to myself or to others – and I believe the doctors involved in my care have been misled to believe this, although in reality I am just an emotional individual, like any other teenage girl" (Exhibit 2, pages 2-3). According to SB, she had not been informed that her vital signs were unstable. SB explained that staff at HSC had waited for her to become unstable to admit her. She had been stable in the emergency room. When she woke up the next morning she had become unstable from receiving no nutrition overnight and was then forced to remain in hospital. (*SB (Re)*, 2017, p. 16)

Adolescent development, if taken into account, may provide a different baseline for the interpretation of these types of behaviours. While it may be that the proper steps were taken, there is no discussion of what role adolescent development plays.

The freedom to grow and learn from mistakes is fundamental to the developmental stage of adolescence and childhood, but in the involuntary treatment hearing context the behaviours associated with this process are framed as oppositional to healing. In many complex ways

throughout the court cases, young people are made out to be straying from their personality due to the illness, but teens are not developmentally expected to have permanent personality traits. It is an interesting interaction that warrants deeper analysis.

### **Unavoidable Forces: the Troubled Teen and the Eating Disorder Monster**

“According to Dr. Dick, JK’s thinking was also influenced by some oppositional tendencies and the classic inability of an adolescent to picture herself as an older person with serious medical issues.” (*JK (Re)*, 2014, p. 9)<sup>16</sup>

There is a shared discussion in academic literature, court cases, and news media of unstoppable and unavoidable developmental forces that impact the child, transitioning into adolescence is viewed as a troubling time for all (Elkind, 1967; Pharo, Sim, Graham, Gross, & Hayne, 2011). The child begins the process constructed as vulnerable and naturally corrupted by the risk taking behaviour of adolescence, otherwise referred to as the “Troubled Teen.” Then comes the diagnosis of an ED, which inflames these behaviours and amplifies the consequences of succumbing to typical teenage behaviours. Risky behaviour is said to be a primary indicator of the adolescent developmental period (Pharo et al., 2011), and within the health care context it is something to avoid at all costs. In court cases, youth are characterized as high risk subjects, who need to be protected from the potentially fatal consequences of their risky behaviours. Further, the ED is often described as a monster that takes hold of the child and inflicts harm, intensifying the ‘symptoms’ of being a troubled teen. In the media articles, death and eating are pitted against each other as rivals and the ED decides which one will prevail. The anthropomorphism of the ED

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<sup>16</sup> This example frames the section, and provides a concrete example of the type of perspectives on adolescence that will be analyzed in this section.

as a vicious and over-powering monster is prevalent in the discourse across both popular and legal sites.

### ***The Troubled Teen***

The “troubled teen” is a fairly common figure of adolescents in the media, in which the adolescent is constructed as dealing with difficult circumstances and sometimes acting out because of this (Nichols & Good, 2004). When it comes to the ED discourse with young people, the troubled teen emerges as a consequence of the diagnosis and produces negative behaviours towards others.

Sometimes, the parents featured in newspaper articles speculate that the ED is part of teenage rebellion. In this *Globe and Mail* newspaper article, a mother wonders how her daughter developed an ED despite her best efforts to raise a happy young woman:

Is this illness her way of rebelling, of separating from her parents? It can't be coincidence for the daughter of a restaurant critic, in a food-centred family, to get an ED. We are very involved parents. We both work at home, we spend weekends alone with our kids, we have high expectations of them. Maybe her illness is a way to break out, a metaphor of refusal to be the daughter we control. EDs love secrecy; she'll almost never talk about it, but the one thing she says is that it's about control, not food. (Kates & Kates, 2003)

Despite an overwhelming amount of medically documented evidence of the biological and medical nature of an ED diagnosis, the social elements are still pondered by concerned parents, searching for a reason that their child is suffering from this affliction. This mother is attributing the troubled teen behaviour to her daughter's eating disorder as both a causal factor and resulting consequence. The disease is a product of individual will and willfulness.

On the rare occasion that a young person is featured in an article telling the story of their treatment process, they are usually depicted as ‘one of the good ones’ who have been unfairly treated by the mental health system. In this *Globe and Mail* article, a young person shares their experience:

“I’ve tried it all,” the *well-mannered* teen added. “They send me home and it starts all over again. I am just really scared. They’d say to me, Oh you’ve been in a hospital so that’s okay, you’ve dealt with it. And I’m like, No. I’ve sat there in a hospital gown for two weeks and I didn’t learn anything. *I have no clue how to cope.*” (MacDonald, 2013, p. 1) [emphasis added]

This is an interesting contribution to the troubled teen narrative, as it indicates that the young person has been pushed into a cycle of helplessness from which they cannot break free. It implies that the troubled teen is influenced by environmental and biological factors. Further, it provides hope for parents and physicians that, if done correctly, treatment can help. However it also solidifies the dominant narrative of the controlling eating disorder and lack of available resources. It is also interesting that the only time that a young person is featured is when they are willing to be complicit in their own disempowerment: “I’m indebted to Dr. Mark Norris” (Britton, 2014, p. 1, *Ottawa Citizen*). Another example is found in the *Ottawa Citizen*: “I was able to get medical attention right away only because I was gravely ill and facing the possibility of death. I often wonder if I had endured my stay on the waiting list, would I still be alive today?” (Minichilli, 2003, p. 1). The admission of weakness is framed as positive; they are given a voice but it is not empowering, rather these young people are further disempowered.

In fact this trend emerges in hearing cases as well:

She *conceded* that she had been incapable while she was underweight, but believed she had regained capacity when she achieved her PW. She suggested that everything has changed when she achieved her PW, and although she had previously been in the grip of the illness, that was no longer the case. *While she also said things like “I know there is no guarantee I will recover” and “my eating disorder is very serious”, we found those parts of her evidence to be scripted and rehearsed and inconsistent with the rest of the evidence.* (L (Re), 2009) [emphasis added]

This demonstrates the inclination of young people to support the suggested narrative of disempowerment. Even when these patients comply with the preferred trope of the “broken child” they are accused of engineering their testimony to appeal to the Board’s perception of

young people as incompetent. There was no situation featured in my corpus in which youth voice is utilized to further a narrative of empowerment.

### ***The Eating Disorder Monster***

In many ways across the discourse, the eating disorder is treated as a monster that is out to get the patient and the family. This monster is portrayed to be difficult or impossible to beat, and as always destructive. The anthropomorphized version of the ED is a dominant part of the discourse regardless of platform. It is utilized often to convey the severity of the illness in court cases and the high prevalence of the illness in newspaper articles.

An interesting observation that can be drawn from the following excerpt is that the disease is being treated as an enemy, uniting the patient and doctor in the face of imminent trouble.

The approach described by Dr. Pinhas was that of a “team approach”. It involved pediatricians, dieticians, psychiatrists, psychologists and others. Team meetings were held on a regular basis and entries made by staff in the patient’s clinical chart were reviewed frequently so as to monitor the individual’s status. The team attempted to engage the patients in dialogue and to establish an alliance. (*BF (Re)*, 2005, p. 4)

Instead of treating the patient as an active member of the team, this excerpt indicates that the patient is only an *ally* in the fight against the eating disorder. This is not the framing of a meaningful partnership focused on wellbeing, but rather, is the treatment professionals inviting the patient to fight *alongside* them as they (the heroes of the story) attempt to beat the ED.

In the court cases, the ED is quite literally given a voice that is channelled through the young person, but does not represent their desires or thoughts. Rather, it is portrayed as having its own agenda of destruction and illness.

Essentially she said whatever she thought she needed to in order to get out of the treatment she was in. Yet she told us that she wanted to recover. Those two did not go together, and

were evidence to us that what we were really hearing was the ED, not L herself. (*L (Re)*, 2009, p. 18)

This narrative pits death and eating against each other, making them mutually exclusive for the patient with the ED. Newspaper articles lean into the conceptualization of the monster as having voice too, as shown here in the *Toronto Star*:

The insidious voice of anorexia nervosa is the most deadly of psychiatric disorders. It can make its sufferers, often astonishingly bright young women, shun food until their skin stretches taut across their skeletal frames. It can make looking in a mirror a dangerous act, or wearing jeans unbearable, since jutting hip bones get rubbed raw by the rough fabric. And for some, it can make eating a plate of food more frightening than death. (Ogilvie, 2008, p. 1)

This quotation is full of adjectives painting a vivid picture that replaces the person who is ordinarily “astonishingly bright” with an angry monster. The perspective of the person behind the monster is removed completely in this narrative. The ED actually claims agency as an actor, capable of change and inflicting pain. Across the discourse, it is agreed that this monster has not only invaded the lives of young people in Ontario, but is almost impossible to stop without help: “unless these existing programs are available to more people sooner, this chronic illness will remain: ruthless, unrelenting, dominant and never-ending” (Minichilli, 2003, p. 1, *Ottawa Citizen*). Newspaper articles and court cases alike emphasize the ways in which professionals could have fought past the monster of the ED if they only had the right resources to do so, at the right time. Every single actor involved in the treatment of EDs in young people seems to agree that the solutions are beyond their understanding and reach due to lack of investment in the area. In order to defeat the ED monster, it is essential to understand it, and unite against it.

The child is depicted as broken, in need of fixing by others, which further solidifies the narrative of the always vulnerable child. An added layer of the prominent portrayal of mental illness as equated with weakness, continues this construction. Discourses of childhood

empowerment and disempowerment are propelled by popular and legal portrayals of weakness and illness.

## Chapter 6

### Conclusion

The constitution of madness as a mental illness[...] affords the evidence of a broken dialogue, posits the separation as already effected, and thrusts into oblivion all those stammered, imperfect words without fixed syntax in which the exchange between madness and reason was made. The language of psychiatry, which is a monologue of reason about madness, has been established only on the basis of such a silence.  
(Foucault & Cooper, 2007, p. xii)

I have worked with young people for over 5 years now, and in this work I was always passionate about providing opportunities for youth voices to be heard. This goal was always at the forefront of my academic and applied work, without much question. It can be stated that ultimately all actors involved are aiming towards the ultimate goal of wellness for the youth, despite having varying levels of agreement about other variables such as independence. This is where voice begins to surface. I used to firmly believe that advocacy and research in youth mental health should be primarily centered on promoting youth voice in policy forums. However as I researched my project, this belief began to feel quite over-simplified. I realized that it is not enough to merely push for more youth voices. Increasing youth voice is great, but providing frameworks that actually create meaningful opportunities and support for youth, is better. I realized that youth voice is not always synonymous with youth agency and that any exercise of youth agency in the mental health context is entangled in a larger, messy complex of intersecting and interacting agencies. In order to advocate to insert youth voices into the conversation, it is crucial to first understand the complexities of the conversation around mental health and youth.

Watching the documentary *Don't Call Me Crazy* (Dedman & Baker, 2013) helped me to begin exploring the discourses surrounding youth with mental illness. My attention narrowed on the complex ways in which Beth's case was talked about and portrayed individually and as part of larger social discussions. It was clear from the beginning that issues of defining and

interpreting agency in relation to constructions of adolescent agency, was woven throughout discussions with and about Beth. This girl's case drew my attention to the magnitude of the discussion taking place around youth and mental health care in relation to bodily autonomy. I was particularly interested in moments that we could characterize as crises of agency – where youth were being hospitalized against their will. I began to dig into academic literature in the area, and reading legal cases where quasi-judicial boards sat in judgement of youth, their families, and the mental health system. I became curious about how these settings related to broader representations of EDs in other cultural locations where we talked about the disease. I was drawn to discourse analysis because it allowed me to connect what I was seeing in the social and popular discourses such as the media, with what was happening in legal settings. I have oriented this project around three main themes: (1) hospitalization experiences: outcome oriented approaches to treatment; (2) the family unit: a source of harm and care; and (3) the patient as a broken child. My findings relate to broader discussions of child and youth studies and health care.

In mental health care there is a clear resource crisis (Levac, 2014; Payne, 2014b, 2015, 2016b; Vallis, 2001) that provides the terrain upon which various actors attempt to navigate and establish various types and levels of agency. It is constantly emphasized that funding is unavailable to adequately support the rising cases of EDs in relevant treatment facilities. Treatment is currently framed as outcome oriented and is built around discourses of compliance. Overloaded systems share some of the blame in these discourses for the lack of available treatment for these individuals. Experts within these systems say that even they are not equipped to handle the “epidemic” that is EDs in adolescent girls today (“Breaking through stigma in the

battle for better eating disorders care in Canada,” 2012; Dr. Clare Roscoe, n.d.; Levac, 2014; Robinson et al., 2013; Vallis, 2001).

The indication that EDs are spreading like wildfire induces a collective feeling of horror and panic, as everyone attempts to navigate the social world they find themselves in. Symptoms are catastrophized, and progress is minimized in order to depict patients as helpless to the ED, incapable of independent change. Fear is incited as a vehicle for change, in which parents and stakeholders are encouraged to fear the ED and panic about the implications of reportedly increasing rates of ED diagnoses in adolescent girls. Further, they are encouraged to rely on experts in the field despite claims by experts that they do not have the financial backing to acquire a sufficient knowledge base or treatment environment to make a meaningful impact on the lives of ED patients (Levac, 2014). Each actor tries to stake a claim over certain areas in the struggle to maintain or obtain agentic roles, while dealing with increasing rates of ED diagnoses in adolescents and children.

The current landscape for youth mental health treatment prioritizes protection over autonomy, particularly in cases where death is possible, or probable. Understandably, given the physical nature of the illness (Cullen, 2010), stakeholders in these communities are using medicalized methods in hospitals to treat ED patients. Little attention is paid to the potential side effects of using characteristics of EDs (e.g. hyper control, focus on weight, isolation, success and failure dichotomies, and a focus on death as a possible outcome) in the treatment of these disorders. Treatment is framed as outcome oriented, and is built around the same characteristics that define having an ED. Weight is in fact at the centre of the treatment discourse for the physicians and parents involved. Youth are only expected to focus on weight and body image if they do so in the ways prescribed by the experts (e.g. gaining weight, rather than losing weight).

The discourse frames the patients in and through their weight as the most central characteristic of their identity, and the measure of their worth.

Often, relying on experts can mediate feelings of panic for those reading about health care crises (Kitzinger, 1999; Kitzinger & Williams, 2005). Providing expertise in an area is meant to provide a feeling of calm in the face of described chaos. The discourses frame expertise as truth and in these texts it is not questioned by anyone. In the cases, if youth question the experts, they are disciplined. Their resistance is depicted as the lack of logical thinking capacity, and is used against them in court cases. This creates the figure of the expert as authority and frames them as having the greatest amount of agency in the discourse. They are relied upon by decision-makers to assess the capacity of the patients, thereby speaking for them or speaking for the disease. Given that mental illness often carries a stigma of irrationality (Sygo, 2015; Yeshua-Katz & Martins, 2013), it is not surprising that this was found in this thesis. .

Reading legal cases in which patients are essentially put on trial for wanting independence, was difficult for me as a passionate youth worker. Coercive treatment is surprisingly blatant in court cases as well as newspaper articles. The word “threat” is used liberally, and is usually used in relation to the patient’s capacity. Emphasis on compliance is evident here, as compliance is equated consistently with capacity. The complete removal of agency was evident, and surprisingly so, given the general orientation of ethics-based discourses to rely on informed consent as a non-negotiable component of ethical treatment (Grover, 2003; J. Harris & Holm, 2003; Panneton, 1977; Weithorn & Campbell, 1982). While I had an inkling as to the issue of youth agency effacement in court proceedings, I had no idea that I would find stories of what I would call the blatant abuse of power at the systemic structural level. These findings support the suggestion that there is an imbalanced power relation between physician and

patient that is at play in mental health hospital settings -- clearly reinforced in legal settings -- which significantly disempowers the youth.

Parents are framed as essential to the healing process of ED patients. This was evident in my analysis, and was consistent with larger discussions of family-oriented approaches to care (Hoadley et al., 2017; Mayer & McKenzie, 2017). They are also considered at least partially responsible for the development of the ED in the first place, not inconsistent with models of parenting in sociological and psychological discourses (Diekema, 2004; Herr, 1986; Rein Lescastereyres, 2015; Ungar, 2004). Parents are depicted as essential to the entire process, regardless of the way in which they contribute. Ultimately, the goal of legal decision makers is shown to be to orient “dysfunctional” and “harmful” families to become “functional” and essential to the healing and treatment process in active ways. Sometimes, the expert becomes a parental figure in the treatment process and is depicted to be a form of “saviour”. The parents in these cases demonstrate that they will relinquish complete control and discretion to the physician and treatment team to fit the definition of the “functional” or “good” family. Within the discourse of health care, placing responsibility on caregivers is not uncommon (Lafrance, 2017; Sibeoni et al., 2017; Sykes, 2006; Ungar, 2004), and provides a figure to place at fault at the center of this issue, rather than addressing larger structural gaps.

Young people with EDs are truly in an impossibly difficult position. They are attempting to learn who they are, as any adolescent (Casey et al., 2008), but are under a microscope where their micro-failures are amplified and discussed at length. There is little room for error as they develop and grow into individuals who have agency; they must learn without mistakes or face serious consequences in the form of formal designation as incapacitated. The construct of young people having decision-making power is not even given the fallacy of presentation; in most

cases, it is directly stated that this does not and cannot exist in a legal context. In this sense, adolescence is being treated simultaneously as a time of childhood, and adulthood, wherein policy makers pick and choose what they need from each area in order to promote compliance. Often under the guise of suggesting safety as the most important factor, policies are set up to provide legislative frameworks that allow for forced compliance, as evidenced in this project.

Currently, attempts at regulating bodies of women and children are at the forefront of political conversations in Ontario, Canada, and more broadly in global conversations about feminism and bodily autonomy (Faith, Pinhas, Schmelefske, & Bryden, 2003; A. Harris, 2003; Hauge, 2009; Schiebinger, 2000). The conversations about what exactly the government should be regulating in relation to citizens' bodies are not new, and are often centered around women and children as key members of society in need of protection, from themselves and others. Often the voices that are actually present in these discourses are those who actively comply (depicted positively), and those who actively resist (depicted negatively) (Bould et al., 2016; A. Harris, 2003, 2004; Jones, Bennett, Olmsted, Lawson, & Rodin, n.d.). The findings of my project in relation to which voices are present, and which are absent, expand upon existing notions of female and youth disempowerment in popular and academic discourses.

The negative connotation of the word irrational, and its placement on young women, fits existing depictions of women and girls that has prevailed in many locations and media (A. Harris, 2003; Hauge, 2009). The marked history of designating women as hysterical beings, incapable of emotional regulation, has direct parallels to child and youth conceptualizations in my discursive sites (Schiebinger, 2000). These discourses are intertwined further by the fact that ED patients are dealing with body related autonomy issues in treatment, and are mostly young females (Abrams & Stormer, 2002; Hill, 2015). These overlapping discourses are not unheard of,

and make the findings of this project – that youth with EDs are struggling to obtain agentic roles in the decision making processes related directly to their physical and mental wellbeing -- unsurprising. Discussing the ED as a driving force that overrides any personality traits of the young person does a disservice to youth. This contributes to disempowerment discourses of females and adolescents which favour the stories of teenage girls who fit the picture of a “good girl” who is harmless, and sweet. There is no room for the girl who experiences emotional turbulence in the discourse of intelligence and capacity, as emotion is seen to be the antithesis of logic (Bandes, 2009; Jasper, 2011) in legal and medical discourses.

The patient with an ED is written as especially helpless, delicate, and even as “broken.” This depiction as broken occurs due to the use of language of the need to fix and repair the damage inflicted by the ED, on the already, always, vulnerable child (Gilligan, 2009; James & Prout, 2003). The construction of the ED as an unbeatable and monstrous force, further subjugates the patient. Within these mediations of illness, there are certain unrealistic expectations thrust upon patients: young people are presumed to be illogical thinkers but are also expected to make logical decisions. These competing expectations provide an impossible depiction of the patient as evolving yet maintain a personality that is constant and free of change, contributing to the portrayal of youth as unstable. Adding to the confusion of this already complicated process, is the discourse of the young person as a passive actor. The various ways that the youth are spoken about, and their voices coopted, prevents them from acting in their own situation, from asserting their autonomy. This finding adds to the already existing orientations towards privileging opinions of adults over those of youth in the medical context. Youth agency is, ironically, further removed and trivialized as part of the outcome-oriented model of striving for total wellness. This is particularly striking in the cases I examined.

I noted that, in both sites of discourse, the ED is portrayed as a monster creeping into the lives of almost *all* young people in Ontario, preying on vulnerability and imposing a characterization of fragility. The descriptions of EDs in anthropomorphized ways, are utilized as fear-inducing strategies in popular and legal discourses. This affective discourse impacted me as I read, and I am not a parent. In imagining the significant impact this type of construction of illness can have on parents who are the target readers of these articles, I was struck with overwhelming sympathy. It is clear that this type of discussion of EDs as unavoidable and insidious, can influence the ways in which parents, patients, and physicians think about EDs. The onlookers are encouraged to feel scared, guilty, and above all, individually responsible for the fate of their adolescent daughters. When an illness is separated from a population, it makes people feel safe and removed from the situation; with ED discourses readers are invited to feel extremely close to the issue, and framed as part of the problem as well as the solution. The agency they are invited to enact is tinged with trauma. The pressure on parents and physicians is immense, and the resulting real-world relationships of these actors may be strained.

On the front line of ED treatment, where the goal is to increase wellness for the patient, there is a very real struggle occurring between safety and engagement shaped by the broader discourses within contemporary mental healthcare. Engaging in this struggle is not easy for any of the actors involved, but notably the young person at the centre is often completely removed from the discussion altogether. This is not to say that young people hold all of the solutions to large-scale mental illness, if they were to be included in the conversation. But physicians and parents are also unable to make a claim of the only expertise, regardless of their level of acquired knowledge, and yet they are included in all discussions regarding youth care. To claim to have all the answers would be naïve for any party; EDs are still being researched at the most basic

level, in various fields, to determine more nuanced understandings of the illness itself (Cullen, 2010; Dr. Clare Roscoe, n.d.). That being said, it also seems unreasonable to exclude the voice of the individual who is at the heart of the issue, the individual actually facing the ED on a daily basis: the patient themselves. Regardless of age, my interpretation of agency would indicate that the right to explore options in relation to one's body is an important right to hold. There can only be gains if the youth with EDs are given more space to speak for themselves.

The understanding of adolescence as a separate developmental period of time is, at this point in child and youth studies, rather uncontroversial, despite variances in agreement on age parameters for this phenomenon (Ben-Amos, 1995; Dubas et al., 2003; Galland, 2003; Hagan & Wheaton, 1993). Yet policy and procedures do not yet exist that specifically address this demographic, aside from assigning an arbitrary age for every regulatory process imaginable in Ontario. Allowing for some flexibility and fluidity between age groups in terms of regulatory documents, alongside specifically developed policies with definitions of adolescence in mind, may provide an opportunity for adolescent specific frameworks in order to better support this demographic.

A similar example in treatment related discourse is the need for gender specific programming (McGuffey, 2008; Pryce, Silverthorn, Sanchez, & DuBois, 2010; Turner, Norman, & Zunz, 1995). There is also a solid push for gender-neutral spaces to be provided as well (Cavanagh, 2013), yet many still argue that having safe spaces that are gender specific provides more opportunities for meaningful engagement in certain types of programming. This is similar to providing adolescent specific programming and policy. It indicates that identifying differences does not always necessarily equate to discrimination, but rather can serve to better support a unique population. Providing adolescent-specific policy regulations would give professionals

clearer guidance on how to go about decision-making processes, and would allow for more of the “typical” teenage behaviours to occur within treatment settings. It also would allow for youth to exercise the right to have more say over their bodies than someone who fits the category of toddler or child, which is currently not the way the landscape is set up to serve children from birth to adulthood (approximately 18-years-old). Policy changes would better inform frontline workers of expectations regarding teens and consent to treatment.

There is a lot of work to be done at the policy level to define adolescence as a period of development that is unique; mistakes are not only acceptable, but *expected* to occur. If this were to be reflected in human rights frameworks, we may see a change in court-systems that are currently set up for adults or young children, and applied to adolescents as if there is no developmental difference. While many argue for young people to be treated more like adults, this argument falls short in many ways of achieving meaningful empowerment (Galland, 2003). Adolescents are fundamentally developmentally different from adults (25+). Policies that influence the treatment of young people should reflect this difference, in order to better protect what is already depicted as a vulnerable population from exploitation or harm such as lengthy involuntary holds and forced feeding. Providing more opportunities for young people to speak their minds, alone, does not meaningfully address the issue of disempowerment, because there is no room for young people in stakeholder positions at this time. We must pay attention to *how* they are accorded agency and the capacity to speak within our policy frameworks.

Today’s adolescents, particularly those with mental illness, are living in the middle of childhood and adulthood, and are not yet able to exercise uniquely constructed human rights or legal frameworks. They are stuck attempting to define their experience against frameworks not meant to be applied to them, and it shows, in court cases, in news media, and in legislation that

fails to address the uniqueness of adolescence. Constructions of youth in popular and legal discourses are not yet set up in a way that supports growth and development, but rather are set up to *discourage* differences and emphasize compliance and conformity. How we talk about these issues matters. It matters a lot. This project has shown that young people in Ontario, are currently not a priority in the eyes of stakeholders. Youth empowerment is a hollow discourse, trumped by a latent discourse of protection that completely erases the agency of patients. In the interlocking web of competing agencies of hospitals, doctors, parents, and the disease itself, there seems little room for the voices of youth to insert themselves into the conversation about them and their mental health. Young people with mental illness are the antithesis of vulnerable; it is time that we start treating them accordingly. We need to do better.

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## Appendix 1

### Demographics of Young People in Court Cases

Case	Age	Gender	Year of Case	Hospital	City	Doctor Primary
AA (Re)	17	Female	2015	Children's Hospital of Eastern Ontario	Ottawa, ON	Dr. Isserlin
AS (Re)	17	Female	2006	London Health Sciences Centre - Victoria Hospital	London, ON	Dr. Couturier
B (Re)	17	Female	2005	Peterborough Regional Health Centre - Civic Site	Peterborough, ON	Dr. Boyer
BF (Re)	14	Female	2005	Hospital for Sick Children	Toronto, ON	Dr. Johnson-Ramgeet
C (Re)	18	Female	2009	Toronto East General and Orthopaedic Hospital	Toronto, ON	Dr. Lemke
CS (Re)	13	Female	2017	Hamilton Health Sciences - McMaster Hospital	Hamilton, ON	Dr. Couturier
GB (Re)	15	Female	2012	Centre for Addiction and Mental Health - Queen Street	Toronto, ON	Dr. Nguyen
H (Re)	15	Female	2011	Children's Hospital of Eastern Ontario	Ottawa, ON	Dr. Temple
HW (Re)	16	Female	2005	Hospital for Sick Children	Toronto, ON	Dr. Bryden
JK (Re)	16	Female	2014	Grey Bruce Health Services	Owen Sounds, ON	Dr. Dick
JQ (Re)	16	Female	2011	Hamilton Health Sciences - McMaster Hospital	Hamilton, ON	Dr. Couturier
JS (Re)	16	Female	2018	Centre for Addiction and Mental Health - Queen Street	Toronto, ON	Dr. Nguyen
L (Re)	17	Female	2009	Hospital for Sick Children	Toronto, ON	Dr. Pinhas
LC (Re)	15	Female	2002	Hospital for Sick Children	Toronto, ON	Dr. Pinhas
MW (Re)	16	Female	2014	Hamilton Health Sciences - McMaster Hospital	Hamilton, ON	Dr. Couturier
NZ (Re)	17	Female	2012	Hamilton Health Sciences - McMaster Hospital	Hamilton, ON	Dr. Couturier
OP (Re)	13	Female	2017	London Health Sciences Centre	London, ON	Dr. Abramson
RJ (Re)	16	Female	2017	Children's Hospital of Eastern Ontario	Ottawa, ON	Dr. Isserlin
SB (Re)	15	Female	2017	Hospital for Sick Children	Toronto, ON	Dr. Steinegger
SJN (Re)	17	Female	2006	Hospital for Sick Children	Toronto, ON	Dr. Pinhas
SL (Re)	18	Female	2016	North York General Hospital	Toronto, ON	Dr. Stein
VB (Re)	17	Female	2005	Peterborough Regional Health Centre - Civic Site	Peterborough, ON	Dr. Boyer
WZ (Re)	17	Female	2010	North York General Hospital	Toronto, ON	Dr. Leonard

In looking at demographic data on the cases, I have some basic things to note about the population at hand. In terms of reported gender, 100% of the court cases were identified as female, which is to be expected given the higher diagnostic prevalence of eating disorders in young females over young males. There are many reasons for this diagnostic trend, however it is beyond the scope of this paper to analyze this in detail. The average age of participants was 16-years-old, with 13 being the youngest and 18 being the oldest; there were the most 17-year-olds (8) and the least 14-year-olds (1). This table has been provided to give the exact demographics of the cases. Most cases took place in the Greater Toronto Area, with Hospital for Sick Children, and Hamilton Health Services - McMaster Hospital as the main treatment centres.

## Appendix 2

### Form 1 – Application for Psychiatric Assessment, Box A

#### Box A – Section 15(1) of the Mental Health Act Serious Harm Test

##### The Past / Present Test *(check one or more)*

I have reasonable cause to believe that the person:

- has threatened or is threatening to cause bodily harm to himself or herself
- has attempted or is attempting to cause bodily harm to himself or herself
- has behaved or is behaving violently towards another person
- has caused or is causing another person to fear bodily harm from him or her; or
- has shown or is showing a lack of competence to care for himself or herself

I base this belief on the following information *(you may, as appropriate in the circumstances, rely on any combination of your own observations and information communicated to you by others.)*

My own observations:

Facts communicated to me by others:

##### The Future Test *(check one or more)*

I am of the opinion that the person is apparently suffering from mental disorder of a nature or quality that likely will result in:

- serious bodily harm to himself or herself,
- serious bodily harm to another person,
- serious physical impairment of himself or herself

I base this opinion on the following information *(you may, as appropriate in the circumstances, rely on any combination of your own observations and information communicated to you by others.)*

My own observations:

Facts communicated by others:

### Appendix 3

#### Form 1 – Application for Psychiatric Assessment, Box B

**Box B – Section 15(1.1) of the Mental Health Act**  
**Patients who are Incapable of Consenting to Treatment and Meet the Specified Criteria**

**Note: The patient *must* meet the criteria set out in *each* of the following conditions.**

I have reasonable cause to believe that the person:

1. Has previously received treatment for mental disorder of an ongoing or recurring nature that, when not treated, is of a nature or quality that likely will result in one or more of the following: *(please indicate one or more)*
  - serious bodily harm to himself or herself,
  - serious bodily harm to another person,
  - substantial mental or physical deterioration of himself or herself, or
  - serious physical impairment of himself or herself;

AND

2. Has shown clinical improvement as a result of the treatment.

AND

I am of the opinion that the person,

3. Is incapable, within the meaning of the *Health Care Consent Act, 1996*, of consenting to his or her treatment in a psychiatric facility and the consent of his or her substitute decision-maker has been obtained;

AND

5. Given the person's history of mental disorder and current mental or physical condition, is likely to: *(choose one or more of the following)*

- cause serious bodily harm to himself or herself, or
- cause serious bodily harm to another person, or
- suffer substantial mental or physical deterioration, or
- suffer serious physical impairment

I base this opinion on the following information *(you may, as appropriate in the circumstances, rely on any combination of your own observations and information communicated to you by others.)*

My own observations:

Facts communicated by others:

## Appendix 4

### Form 2 – Order for Examination

#### Part A – Subsection 16 (1)

Information has been brought before me that such person

- has threatened or attempted or is threatening or attempting to cause bodily harm to himself or herself;
- has behaved or is behaving violently towards another person or has caused or is causing another person to fear bodily harm from him or her; or
- has shown or is showing a lack of competence to care for himself or herself.

In addition based upon the information before me I have reasonable cause to believe that the person is apparently suffering from mental disorder of a nature or quality that likely will result in,

- serious bodily harm to the person;
- serious bodily harm to another person, or
- serious physical impairment of the person.

#### Part B – Subsection 16 (1.1)

Information has been brought before me that such person

- a) has previously received treatment for mental disorder of an ongoing or recurring nature that, when not treated, is of a nature or quality that likely will result in serious bodily harm to the person or to another person or substantial mental or physical deterioration of the person or serious physical impairment of the person; and
- b) has shown clinical improvement as a result of the treatment;

In addition based upon the information before me I have reasonable cause to believe that the person,

- c) is apparently suffering from the same mental disorder as the one for which he or she previously received treatment or from a mental disorder that is similar to the previous one;
- d) given the person's history of mental disorder and current mental or physical condition, is likely to
  - cause serious bodily harm to himself or herself;
  - cause serious bodily harm to another person,
  - suffer substantial mental or physical deterioration of the person, or
  - suffer serious physical impairment of the person; and
- e) is apparently incapable within the meaning of the *Health Care Consent Act*, 1996 of consenting to his or her treatment in a psychiatric facility and the consent of his or her substitute decision-maker has been obtained.

Now therefore, I order you, the said police officers, or any of you, to take the said person in custody forthwith to an appropriate place for examination by a physician.

(Ministry of Health and Long-Term Care, Mental Health Branch, 2000b)

## Appendix 5

### Form 3 – Certificate of Involuntary Admission

#### Box A – Risk of Serious Harm

**Note: Check one or more boxes as appropriate.**

The patient is suffering from mental disorder of a nature or quality that likely will result in:

- serious bodily harm to the patient,
- serious bodily harm to another person
- serious physical impairment of the patient

unless he or she remains in the custody of a psychiatric facility.

#### Box B – Patients who are Incapable of Consenting to Treatment and Meet the Specified Criteria (continued)

3. The patient has shown clinical improvement as a result of the treatment.
4. The patient is suffering from the same mental disorder as the one for which he or she previously received treatment or from a mental disorder that is similar to the previous one.
5. Given the person's history of mental disorder and current mental or physical condition, is likely to:  
(please indicate one or more)
  - cause serious bodily harm to himself or herself, or
  - cause serious bodily harm to another person, or
  - suffer substantial mental or physical deterioration, or
  - suffer serious physical impairment

(Ministry of Health and Long-Term Care, Mental Health Branch, 2000c)

## Appendix 6

### Form 4 – Certificate of Renewal

#### Box A

You must be satisfied that both criteria are met.

I am of the opinion that

1. The patient is suffering from mental disorder of a nature or quality that likely will result in:  
(choose one or more of the following)

- serious bodily harm to the patient,  
 serious bodily harm to another person,  
 serious physical impairment of the patient,

unless he or she remains in the custody of a psychiatric facility; and

2. The patient is not suitable for continuation as an informal or voluntary patient.

#### Box B

You must be satisfied that all six criteria are met.

I am of the opinion that

1. the patient has been found incapable, within the meaning of the *Health Care Consent Act, 1996* of consenting to his or her treatment in a psychiatric facility and the consent of his or her substitute decision-maker has been obtained,

AND

2. the patient has previously received treatment for mental disorder of an ongoing or recurring nature that, when not treated, is of a nature or quality that likely will result in (choose one or more of the following)

- serious bodily harm to the patient,  
 serious bodily harm to another person,  
 substantial mental or physical deterioration of the patient, or  
 serious physical impairment of the patient,

AND

3. has shown clinical improvement as a result of the treatment,

AND

4. is suffering from the same mental disorder as the one for which he or she previously received treatment or from a mental disorder that is similar to the previous one,

AND

5. given the patient's history of mental disorder and current mental or physical condition, is likely to (choose one or more of the following)

- cause serious bodily harm to himself or herself,  
 cause serious bodily harm to another person,  
 suffer substantial mental or physical deterioration,  
 suffer serious physical impairment;

AND

6. the patient is not suitable for continuation as an informal or voluntary patient.

(Ministry of Health and Long-Term Care, Mental Health Branch, 2000d)

## Appendix 7

### Form 4A – Certificate of Continuation

#### Box A

**You must be satisfied that both criteria are met.**

I am of the opinion that

- 1 The patient is suffering from mental disorder of a nature or quality that likely will result in:  
(choose one or more of the following)

- serious bodily harm to the patient,  
 serious bodily harm to another person,  
 serious physical impairment of the patient,

unless he or she remains in the custody of a psychiatric facility; and

- 2 The patient is not suitable for continuation as an informal or voluntary patient.

#### Box B

**You must be satisfied that all six criteria are met.**

I am of the opinion that

- 1 the patient has been found incapable, within the meaning of the Health Care Consent Act, 1996 of consenting to his or her treatment in a psychiatric facility and the consent of his or her substitute decision-maker has been obtained,

AND

- 2 the patient has previously received treatment for mental disorder of an ongoing or recurring nature that, when not treated, is of a nature or quality that likely will result in (choose one or more of the following)

- serious bodily harm to the patient,  
 serious bodily harm to another person,  
 substantial mental or physical deterioration of the patient, or  
 serious physical impairment of the patient,

AND

- 3 has shown clinical improvement as a result of the treatment,

AND

- 4 is suffering from the same mental disorder as the one for which he or she previously received treatment or from a mental disorder that is similar to the previous one,

AND

- 5 given the patient's history of mental disorder and current mental or physical condition, is likely to  
(choose one or more of the following)

- cause serious bodily harm to himself or herself,  
 cause serious bodily harm to another person,  
 suffer substantial mental or physical deterioration,  
 suffer serious physical impairment;

AND

- 6 the patient is not suitable for continuation as an informal or voluntary patient.

(Ministry of Health and Long-Term Care, Mental Health Branch, 2015)

## Appendix 8

### *HCCA Consent to Treatment*

#### **No treatment without consent**

10 (1) A health practitioner who proposes a treatment for a person shall not administer the treatment, and shall take reasonable steps to ensure that it is not administered, unless,

(a) he or she is of the opinion that the person is capable with respect to the treatment, and the person has given consent; or

(b) he or she is of the opinion that the person is incapable with respect to the treatment, and the person's substitute decision-maker has given consent on the person's behalf in accordance with this Act. 1996, c. 2, Sched. A, s. 10 (1).

#### **Opinion of Board or court governs**

(2) If the health practitioner is of the opinion that the person is incapable with respect to the treatment, but the person is found to be capable with respect to the treatment by the Board on an application for review of the health practitioner's finding, or by a court on an appeal of the Board's decision, the health practitioner shall not administer the treatment, and shall take reasonable steps to ensure that it is not administered, unless the person has given consent. 1996, c. 2, Sched. A, s. 10 (2).

#### **Elements of consent**

11 (1) The following are the elements required for consent to treatment:

1. The consent must relate to the treatment.

2. The consent must be informed.

3. The consent must be given voluntarily.

4. The consent must not be obtained through misrepresentation or fraud. 1996, c. 2, Sched. A, s. 11 (1).

#### **Informed consent**

(2) A consent to treatment is informed if, before giving it,

(a) the person received the information about the matters set out in subsection (3) that a reasonable person in the same circumstances would require in order to make a decision about the treatment; and

(b) the person received responses to his or her requests for additional information about those matters. 1996, c. 2, Sched. A, s. 11 (2).

#### **Same**

(3) The matters referred to in subsection (2) are:

1. The nature of the treatment.

2. The expected benefits of the treatment.

3. The material risks of the treatment.

4. The material side effects of the treatment.

5. Alternative courses of action.

6. The likely consequences of not having the treatment. 1996, c. 2, Sched. A, s. 11 (3).

#### **Express or implied**

(4) Consent to treatment may be express or implied. 1996, c. 2, Sched. A, s. 11 (4).

#### **Included consent**

12 Unless it is not reasonable to do so in the circumstances, a health practitioner is entitled to presume that consent to a treatment includes,

(a) consent to variations or adjustments in the treatment, if the nature, expected benefits, material risks and material side effects of the changed treatment are not significantly different from the nature, expected benefits, material risks and material side effects of the original treatment; and

(b) consent to the continuation of the same treatment in a different setting, if there is no significant change in the expected benefits, material risks or material side effects of the treatment as a result of the change in the setting in which it is administered. 1996, c. 2, Sched. A, s. 12.

#### **Plan of treatment**

13 If a plan of treatment is to be proposed for a person, one health practitioner may, on behalf of all the health practitioners involved in the plan of treatment,

(a) propose the plan of treatment;

(b) determine the person's capacity with respect to the treatments referred to in the plan of treatment; and

(c) obtain a consent or refusal of consent in accordance with this Act,

(i) from the person, concerning the treatments with respect to which the person is found to be capable, and

(ii) from the person's substitute decision-maker, concerning the treatments with respect to which the person is found to be incapable. 1996, c. 2, Sched. A, s. 13.

#### **Withdrawal of consent**

14 A consent that has been given by or on behalf of the person for whom the treatment was proposed may be withdrawn at any time,

(a) by the person, if the person is capable with respect to the treatment at the time of the withdrawal;

(b) by the person's substitute decision-maker, if the person is incapable with respect to the treatment at the time of the withdrawal. 1996, c. 2, Sched. A, s. 14.

(Health Care Consent Act, 1996)

## Appendix 9

### *HCCA Consent on Incapable Person's Behalf*

#### **Consent**

##### **List of persons who may give or refuse consent**

20 (1) If a person is incapable with respect to a treatment, consent may be given or refused on his or her behalf by a person described in one of the following paragraphs:

1. The incapable person's guardian of the person, if the guardian has authority to give or refuse consent to the treatment.
2. The incapable person's attorney for personal care, if the power of attorney confers authority to give or refuse consent to the treatment.
3. The incapable person's representative appointed by the Board under section 33, if the representative has authority to give or refuse consent to the treatment.
4. The incapable person's spouse or partner.
5. A child or parent of the incapable person, or a children's aid society or other person who is lawfully entitled to give or refuse consent to the treatment in the place of the parent. This paragraph does not include a parent who has only a right of access. If a children's aid society or other person is lawfully entitled to give or refuse consent to the treatment in the place of the parent, this paragraph does not include the parent.
6. A parent of the incapable person who has only a right of access.
7. A brother or sister of the incapable person.
8. Any other relative of the incapable person. 1996, c. 2, Sched. A, s. 20 (1); 2016, c. 23, s. 51 (1).

#### **Requirements**

- (2) A person described in subsection (1) may give or refuse consent only if he or she,
- (a) is capable with respect to the treatment;
  - (b) is at least 16 years old, unless he or she is the incapable person's parent;
  - (c) is not prohibited by court order or separation agreement from having access to the incapable person or giving or refusing consent on his or her behalf;
  - (d) is available; and
  - (e) is willing to assume the responsibility of giving or refusing consent. 1996, c. 2, Sched. A, s. 20 (2).

#### **Ranking**

- (3) A person described in a paragraph of subsection (1) may give or refuse consent only if no person described in an earlier paragraph meets the requirements of subsection (2). 1996, c. 2, Sched. A, s. 20 (3).

#### **Same**

- (4) Despite subsection (3), a person described in a paragraph of subsection (1) who is present or has otherwise been contacted may give or refuse consent if he or she believes that no other person described in an earlier paragraph or the same paragraph exists, or that although such a person exists, the person is not a person described in paragraph 1, 2 or 3 and would not object to him or her making the decision. 1996, c. 2, Sched. A, s. 20 (4).

#### **No person in subs. (1) to make decision**

(5) If no person described in subsection (1) meets the requirements of subsection (2), the Public Guardian and Trustee shall make the decision to give or refuse consent. 1996, c. 2, Sched. A, s. 20 (5).

#### **Conflict between persons in same paragraph**

(6) If two or more persons who are described in the same paragraph of subsection (1) and who meet the requirements of subsection (2) disagree about whether to give or refuse consent, and if their claims rank ahead of all others, the Public Guardian and Trustee shall make the decision in their stead. 1996, c. 2, Sched. A, s. 20 (6).

#### **Meaning of “spouse”**

(7) Subject to subsection (8), two persons are spouses for the purpose of this section if,

- (a) they are married to each other; or
- (b) they are living in a conjugal relationship outside marriage and,
  - (i) have cohabited for at least one year,
  - (ii) are together the parents of a child, or
  - (iii) have together entered into a cohabitation agreement under section 53 of the *Family Law Act*. 1996, c. 2, Sched. A, s. 20 (7); 2004, c. 3, Sched. A, s. 84 (1-3).

#### **Not spouse**

(8) Two persons are not spouses for the purpose of this section if they are living separate and apart as a result of a breakdown of their relationship. 2004, c. 3, Sched. A, s. 84 (4).

#### **Meaning of “partner”**

(9) For the purpose of this section, “partner” means,

- (a) Repealed: 2004, c. 3, Sched. A, s. 84 (5).
- (b) either of two persons who have lived together for at least one year and have a close personal relationship that is of primary importance in both persons’ lives. 2002, c. 18, Sched. A, s. 10; 2004, c. 3; Sched. A, s. 84 (5, 6).

#### **Meaning of “relative”**

(10) For the purposes of this section, a relative includes a person related to another person by marriage or adoption. 2016, c. 23, s. 51 (2).

#### **Meaning of “available”**

(11) For the purpose of clause (2) (d), a person is available if it is possible, within a time that is reasonable in the circumstances, to communicate with the person and obtain a consent or refusal. 1996, c. 2, Sched. A, s. 20 (11).

#### **Best interests**

(2) In deciding what the incapable person’s best interests are, the person who gives or refuses consent on his or her behalf shall take into consideration,

- (a) the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable;
- (b) any wishes expressed by the incapable person with respect to the treatment that are not required to be followed under paragraph 1 of subsection (1); and
- (c) the following factors:
  1. Whether the treatment is likely to,
    - i. improve the incapable person’s condition or well-being,
    - ii. prevent the incapable person’s condition or well-being from deteriorating, or

- iii. reduce the extent to which, or the rate at which, the incapable person's condition or well-being is likely to deteriorate.
- 2. Whether the incapable person's condition or well-being is likely to improve, remain the same or deteriorate without the treatment.
- 3. Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her.
- 4. Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed. 1996, c. 2, Sched. A, s. 21 (2).

### **Information**

22 (1) Before giving or refusing consent to a treatment on an incapable person's behalf, a substitute decision-maker is entitled to receive all the information required for an informed consent as described in subsection 11 (2). 1996, c. 2, Sched. A, s. 22.

### **Conflict**

(2) Subsection (1) prevails despite anything to the contrary in the *Personal Health Information Protection Act, 2004*. 2004, c. 3, Sched. A, s. 84 (7).

### **Ancillary treatment**

23 Authority to consent to a treatment on an incapable person's behalf includes authority to consent to another treatment that is necessary and ancillary to the treatment, even if the incapable person is capable with respect to the necessary and ancillary treatment. 1996, c. 2, Sched. A, s. 23.

### **Admission to hospital, etc.**

24 (1) Subject to subsection (2), a substitute decision-maker who consents to a treatment on an incapable person's behalf may consent to the incapable person's admission to a hospital or psychiatric facility or to another health facility prescribed by the regulations, for the purpose of the treatment. 1996, c. 2, Sched. A, s. 24 (1).

### **Objection, psychiatric facility**

(2) If the incapable person is 16 years old or older and objects to being admitted to a psychiatric facility for treatment of a mental disorder, consent to his or her admission may be given only by,

- (a) his or her guardian of the person, if the guardian has authority to consent to the admission; or
- (b) his or her attorney for personal care, if the power of attorney contains a provision authorizing the attorney to use force that is necessary and reasonable in the circumstances to admit the incapable person to the psychiatric facility and the provision is effective under subsection 50 (1) of the *Substitute Decisions Act, 1992*. 1996, c. 2, Sched. A, s. 24 (2).

(Health Care Consent Act, 1996)