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Reflections on Personhood: Girls with Severe Disabilities and the Law

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Abstract

Through a series of reflections employing a legal lens this paper explores the circumscription of the personhood of girls living with severe disabilities. Ideas from the work of Australian legal theorist Ngaire Naffine on the doctrine of the legal person are drawn from and applied to extracts from court documents in Canada and beyond. The at-times contested personhood and evident attempts to un-personify girls with disabilities are reflected upon through the consideration of a series of experiences. These include concerning medical decision making, the acquisition of civil disabilities, the way in which girls with disabilities are valued or not valued and the forms of violence that are perpetrated against them in the troubling area where childhood meets with severe disability and female sex. Reflections include the consideration of the cases of Leilani Muir, Tracy Latimer and other girls whose matters came before decision makers to have legal rights determined.

Key words

Girls, Disabilities, Rights, Personhood, Child, Metaphysical

Reflections on Personhood: Girls with Severe Disabilities and the Law

The prodigies and their families objected to being in a book with the severely disabled…
Andrew Soloman, 2012

Who wrote the book of love?
Davis, Malone and Patrick, 1957

Introduction

Scholars in the area of disability studies use a variety of lenses through which to reflect on the status of persons with disabilities. Some examples are sociological (Thomas, 2007), cultural (Garland-Thomson, 1997), the social model (Oliver, 1990) and the legal lens (Malloy, 2001). Many of those using a legal lens have considered disability rights using an equality rights frame (Lepofsky, 1998; Rioux, 2003). Others have produced scholarly work in overlapping areas, for example (and of relevance to this paper) disability rights and feminism (Frazee, Gilmour and Mykitiuk, 2006). This article, while also employing a legal lens, considers aspects of the doctrine of the legal person. Mine is not a legal article nor it is an exhaustive account of any other scholar's project; rather, it is a series of reflections in which I address what I see as the circumscription of personhood in decisions made about vulnerable girls in law and ethics.[1] Cases I select focus primarily on the experiences of North American girls; however, I also address cases from outside North American jurisdictions, two from the United Kingdom, and a court case involving the late Yael Shefer.

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[1] Many thanks to the anonymous peer reviewers, to Susan Murphy M.Ed. for her editing assistance, and to Jessica Eisen, Michael Miceli, and Catherine Duchastel for their helpful comments on earlier drafts. Any errors are entirely my own.

On Not Being a Person

Soloman (2012) reports that in the late 1960s, *The Atlantic Monthly* carried an article by Joseph Fletcher in which he stated:

> "there was "no reason to feel guilty about putting a Down's Syndrome baby away, whether it's 'put away' in the sense of hidden in a sanitorium or in a more lethal sense. It is sad, yes. Dreadful. But it carries no guilt. **True guilt arises only from the offence against a person, and a Down's is not a person.""** (p.181, author emphasis)

Soloman (2012) relays that parents in that era were persuaded that their own children 'were not persons'. It was because of this, he says, that they found themselves able to leave their children in inhumane conditions. His discussion invites us to reflect on societal inhumanity towards children with disabilities in the not too distant past. Yet, a question that arises from Soloman's (2012) quotation is whether the evident lack in the area of personhood in a child with a disability is a thing of the past or whether in fact aspects of that perceived lack are still with us? I suggest it is still with us to a degree and I propose that various diverse pieces of litigation pertaining to girls with severe disability support this view. In order to reflect upon the situation of girls as seen in litigation concerning them, I draw from (among other things) ideas about law's person as presented by Australian legal theorist Ngaire Naffine. Naffine theorizes about the effects of ideas from religion, science and philosophy on the construction of the legal person in the context of legal rights.

The Legal Requirements of Humanity

Naffine (2004) states "perhaps the most fundamental purpose of the legal invention of the person is to create and endow a being with legal as well as moral values." To personify, she says, is to confer dignity and respect. Flowing from that is the endowment of certain rights and duties[2]. Black’s Law Dictionary (1979) informs us that “persona” in civil law is the character by which certain rights belong to a man and certain duties are imposed upon him. The legal person is therefore (as Naffine points out) an abstract construct. In order to qualify as ‘persons’ in law, Naffine (2003) explains, humans must meet the legal requirements of humanity[3]. Naffine (2003) notes that there have been debates in law about what it is to be a human being, pointing out a lack of consensus on the matter[4]. Yet, as I show below, for some persons, the fact that they meet agreed upon criteria for humanity, on its own, may prove insufficient to ensure that they will experience treatment as persons when they become engaged in processes that involve decision making about their legal rights. The mere fact of being a human being therefore may not guarantee that jurists and others involved in determining the law, or how it will be applied, will necessarily respond to the human before them as a person to be accorded the same rights as other persons in practice. To contemplate this is both disturbing and intriguing and invites pause for reflection. What process renders the legal personality (and humanity) of some persons less

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[2] Children hold legal personality, however, at law their capacity to exercise their legal rights on their own may be circumscribed. Minors can sue with a litigation guardian; children twelve years old and older can often have a say in family court matters that concern them; children can inherit, are protected under law, can testify and so on. Yet, Sykes (2006) points out that “children’s rights, which are conceptually difficult rights of relatively recent vintage, are effectively subsumed into their grown-up counterparts: parental rights, which have long roots in a powerful common law and constitutional tradition” (p. 3). She notes that the United Nations Convention on the Rights of the Child reflects that children “are entitled to the same human rights as all other human beings” but because of their circumstances require a different approach to the protection of their human rights. Sykes (2006) asserts that the 2004 decision in the case Canadian Foundation for Children, Youth and the Law *v.* Canada silences the voices of children, truncates their rights and denies them their autonomy. Why do I mention this case? I mention it because it has established that violence against children will be tolerated in Canada. It also establishes that children are not autonomous, as Sykes notes. Lack of autonomy and no defense against certain forms of bodily assault is the starting point in a discussion about the rights of children, at least in Canada and the United States.

[3] She asks the interesting question of why other sentient beings cannot be legal persons as well.

[4] For example “The first stand-alone personhood legislation arose in Colorado in the form of a ballot initiative in 2008. This Constitutional amendment would have given all persons, "from the beginning of [their] biological development," i.e., from the moment of sperm-egg fertilization, inalienable rights, equality of justice, and due process of law protection under the Colorado Constitution. It was rejected by Colorado voters both in November, 2008, and when presented again in November, 2010, by margins of 2 to 1.)”. (Resolve, 2010)

visible, even though 'the entity' in question is clearly a person in the legal sense (Naffine, 2009)? Later I will draw from case law to demonstrate the process to which I refer[5].

The lack of consensus among jurists on who qualifies as human or as having a legal personality in courts of law has been noted by both Naffine (2003) and Hamilton (2009), and Hamilton (2009) has added that there are 'powerful historical legacies of personhood' (Hamilton, 2009, p. 7). I suggest that ideologies like patriarchy, ableism, and racism are three such legacies. That women have had to struggle to be persons in law is something Naffine (2003, 2009) and Hamilton (2010) both remind us of. It is more obvious to us looking back with hindsight to see how patriarchy and racism have denied legal personhood to certain individuals and groups. A careful examination reveals this same thing takes place for persons with disabilities, however insidiously, even though technically they have rights. It has been stated by at least one noted scholar (Landsman, 2003) that the presence of disability diminishes personhood. Children moreover do not have deeply established rights (Sykes, 2006). Indeed, recognition of children's rights is a recent development, and children's rights jurisprudence is an area of law that remains poorly developed (Sykes, 2006). In light of the above the particular combination of childism, racism, sexism and ableism may work together[6] to threaten the legal personality of some, and this ought to be a concern for children who are disabled, especially if they are female, severely disabled and very young.

Naffine (2003, 2004, 2009, and 2010) in a number of her works presents provocative ideas in asking questions about who law's persons are. In so doing she presents a series of conceptualizations of different sorts of 'persons' who she suggests influence decisions made by

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[5] Others in Canada have done this before me and particularly in the *Latimer* case.

[6] The term that comes to my mind in pondering this rather complex situation is "matrix of domination" as set out by Patricia Hill Collins (2000) in *Black Feminist Thought: Knowledge, Consciousness and the Politics of Empowerment*. Routledge, New York, USA.

jurists and others in law. In asking “*Who are Law’s Persons?”* she explains for the uninitiated that in law a person is technically *a unit* holding both rights and duties**.** This unit is the person that jurists, law makers and lawyers technically consider while deliberating on legal matters that invoke questions pertaining to personhood. Naffine (2009) however also asserts that it is not a simple matter for jurists and others (whom she refers to as law’s interpreters) to operate solely inside the sphere of the artificially constructed legal person. She argues there are in reality constructs of other sorts of persons who make inroads on the thinking, reasoning and decisions of law’s interpreters about the person who appears before them. She refers to these other sorts of persons as being metaphysical persons.

‘Legalists’ and ‘Metaphysical Realists’ as set out by Naffine (2009, p. 21) are different from one another in their approach to personality. Naffine (2009) asserts that legalists state they have “no special insights into the human condition and that it is simply not the law’s business to engage in metaphysical, ontological or existential disputes or determinations” (2009, p. 21). In this regard she points out that the legal person is both formal and neutral as a construct to be used in enabling a legal person to act in law. For this reason she asserts the legalist’s person has little to do with the essential nature of beings.

The metaphysical realists Naffine (2009) describes fall into three groups: rationalists, religionists and naturalists. In formulating personhood, rationalists value reason, religionists rely upon the sanctity of persons to assert their personhood and naturalists she says “regard us as evolved biological creatures” (2009, p. 20). The breaking down of law’s persons in this manner is an exercise Naffine (2009) asserts may assist us in finding out who and what ‘counts’ as a ‘person’ in law and who does not. Hamilton (2010) points out as well that different notions of personhood in society exist (she mentions the medical one for example) but she asserts that who is or is not a person is still fundamentally a legal matter. Whether the medicalists' person falls under the metaphysical rationalist person as set out by Naffine is debatable. It may be that the medicalist's person is fast becoming a presentation of the person in its own right. Moreover medical understanding of who is a person and who is not a person may be one that poses a profound threat to humans who rely heavily on that discipline's interpretation of personhood to be permitted to continue to live. I suggest that this is especially so when it is the severely disabled newborn or baby who is under discussion.

I suggest too that weight should be accorded to Naffine's (2003) important insight that the "definitional problem of the person" (p. 346) is "likely to become more acute with technological and economic progress…" (Naffine, 2003 p. 346) and especially with regard to the matter of children as persons in law. Given the extensive technological and medical advances in the area of child health and the corresponding presence of a new and little understood population of children living with severe disabilities (Carnavale et al, 2008) it has become increasingly apparent that currently held ideas about children *both* in law and medicine are in certain regards deeply troubled by these advances.

Within this new and little understood population of children are girls who live with severe disabilities. Personhood for girls who have congenital disabilities, who live with developmental disabilities or with severe impairments and/or live with chronic pain are at times treated by law's interpreters (to employ Naffine's (2009) language) *as though* they hold less than full personhood. While it is the case that girls *per se* eminently qualify as the legalist's person and as various sorts of metaphysical persons as described by Naffine (2009) as well, they nevertheless at times fail to 'count' as such in legal and in ethical encounters.

Frazee (2012), writing about Tracy Latimer, a Canadian girl with a disability who was killed by her father Robert, asserts "We can and shall reject the dangerous notion that Robert's life is natural, and that Tracy's somehow was not." Her comment sheds light upon the naturalist's person whom Naffine (2009) identifies and one we might assume would be more receptive to conferring a robust personality to someone with a disability. In fact, however, Frazee (2012) demonstrates the way in which the naturalist's person excludes a girl with a severe disability from just that kind of personhood. Frazee (2012), writing about a now famous photograph of Robert Latimer standing on the edge of a cliff overlooking the rugged prairies of Canada, asserts that this portrayal of Latimer, as she notes, patriarch, farmer and steward of nature, is nothing more than a cultural idea. It is, she asserts, one that wrongly holds that girls with severe disabilities are somehow unnatural. This idea is part of Canadian culture and Frazee's (2012) point is well made. It is curious that the process of de-personalization of an innocent 12 year- old girl who was murdered in 1993 continues to be pursued by some in Canada to this day. It is a puzzle to which I will return.

First however, why do I care? I care because, as Naffine (2009) herself notes, there are groupings of case law where the person who is the subject under consideration carries a problematic status. In my view one of these groupings are girls, certain kinds of girls in particular. I care because the use of the words 'person' and 'personhood' in the context of this same case law arise when the 'entity' under discussion is (a) a girl, and (b) one with a significant disability. This would not, I argue, be the case were their personhood not contested. It should go without saying that they are/were persons. However, at some level, it is this very fact that is being contested.

The word 'person' (as Naffine notes) is used by the legalist to mean a "right-and-duty bearing unit'. It is understood that the unit encompasses all in the human family, including, of course, girls living with severe disabilities. Yet, as I have noted, these girls appear at times to lack legal traction. This is not to suggest that these girls are not legal persons, but rather to point out that they are not always treated as such. I am suggesting that some adjudicators and others involved in making decisions about girls with disabilities at times demonstrate curious and uneven levels of responsiveness towards them given their actual status as legal persons. This lower level of responsiveness takes place even though jurists and others would agree that human rights are global and intended for all. On this front, one query I have is whether some of law's interpreters and some others are insufficiently oriented towards girls who are disabled (to use Naffine's language) and if so in what particular ways? It would be helpful to contemplate this from a number of angles, for without grasping this problem there is no foreseeable way to tackle it.

One of the things Naffine (2009) argues (to paraphrase) is that the law, by defining law's person, draws a circle around who is in and who is out vis-a-vis being a protected entity at law. She explains the complex ways in which a being may be a legal person in one setting, but not in another. For example, she points out that the law may allow a foetus to inherit but it may not allow a foetus to sue. In one situation it bears certain kinds of rights, but not in another. Is this what we are seeing with girls with disabilities? Is it the case that they have more rights in some settings than in others? If so, this raises questions about the nature of their rights overall.

Naffine (2010) states that the fundamental question of "who is law for?" has been neglected in the jurisprudence. She herself answers that the law is for persons, adding though that it may not be for 'everyone'. In spite of their being, as humans and as girls, inside the circle of protection of the law, it is clear that the law is not always *for* girls *with severe disabilities*. Encompassed in the question "who is law for?" are other questions such as "whom is it oriented towards? and "whom does it presuppose?" Also, to whom does law respond in a most fulsome manner?

There are many examples of times in history when the law has failed to protect persons. The constitutional jurisprudence in the United States respecting de-segregation offers many examples of this. Where the law is seen not to protect fully there are reasons for that and they appear to be cultural, rooted in society's values about who matters more and who matters less.

The Disabled And The Female

Foetuses whose status is ascertained to be female (Sen, 2001) or anomalous (Strangl, 2010) are more likely than male or able-bodied foetuses to be aborted. The practice of aborting female foetuses at higher rates than male foetuses is more common in the global south and the selective termination of disabled foetuses is assumedly still more common in the global north. Grosz (1996) writes that those with severe disabilities ("gross deformities") are usually the subject of abortion, which she states explains the increasing 'rarity' of individuals who are severely disabled[7].

In an article about selective termination of disabled foetuses, Mykitiuk (2012) states that "…the act of surveillance for and selection against foetuses with these characteristics sends the message that people with these characteristics are less valuable to society, just as the selection of female foetuses sends the message that women are less valuable than men." (np.) Strangl (2010, p. 32) observes that "it is widely thought that abortion on the ground of foetal abnormality is

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[7] I have not found any actual data regarding this.

morally justified" and aspects of personhood relating to this practice and its justification is something she explores. Sen (2001) has referred to selective abortion as high-tech sexism. On reflection, it is evident that selectively aborting female and disabled foetuses *says something* about the lesser value that some people in society place on female sex and disability status. This both is and is not an issue that relates to personhood, at least in Canada, where foetuses are not considered legal persons. Jackson (2000) observes that "Disability should not be a relevant reason for choosing between people, but if one accepts that a foetus does not have legal personality, rules that prohibit discrimination cannot apply in utero…". What he is saying is since anti-discrimination law is for people and since foetuses are not legal persons, they cannot be discriminated against as people. Likewise sex should not be a relevant reason to choose between two people, and if one agrees that foetuses are not law's persons[8] in this context, then selective termination of female foetuses cannot be addressed through equality law provisions either. It may be that my concern here, namely the lower level of the law's responsiveness to the personhood of severely disabled girls will become less and less of a concern over time[9]. Logic would lead one to surmise that there could be a combined effect of these two forms of selective termination in the future[10]. That possibility and the possible ramifications of it open the door to another conversation beyond the scope of this one.

In one sense though, the selective termination of foetuses of the female sex which have disabilities *is* an issue that relates to the personhood of girls with severe disabilities. Caeton (2011) observes that existing tensions between feminist theory and disability theory remain under-theorized, asserting that "feminist theorists all too often do not recognize disability even

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[8] Fascinating case law regarding the rights and lack of rights of the fetus is something Naffine (2009) addresses where she takes up the question of law's person in Law's Meaning of Life (2009).

[9] This is conjecture on my part.

[10] Though there will always be girls who become severely ill and severely disabled through accidents, crimes, illness and so on.

while exploring those feminist issues that are intricately entangled with disability." The reverse is also true and Garland-Thomson (2007) observes that assertions made by many disability theorists show that they have little knowledge of feminist theory. There needs to be more interdisciplinary discussion across the divide of these two domains. Better understanding the reasons why people elect to abort female foetuses and disabled foetuses based on their sex and disability status may teach us something about the reasons girls with severe disabilities may experience difficulties as persons when they encounter law's interpreters and others involved in making critical decisions in their lives.

Girlhood

Naffine's (2009) ideas explored above are potentially useful in considering some of the difficulties children with severe disabilities experience in having their rights recognized and asserted. Rights such as bodily integrity, privacy, the right to reside with their family of origin, the right to be protected under the criminal code, the right to medical treatment, the right to have adequate attention paid to their needs in institutional settings and so on are examples of the kinds of rights to which I refer.

Media reports on children and youth with severe disabilities frequently involve stories about girls and the serious crimes against them. It is unclear whether more girls than boys with disabilities are murdered or whether there is more intense interest regarding the circumstances of their deaths. For example there was a great deal of sensational coverage respecting the murder in the United States of ten year-old Zahra Baker (Herald Sun, 2010). Zahra was an Australian girl who moved with her father to the United States to live with him and with her new step-mother. Zahra had had both bone and lung cancer, a partial leg amputation, used a prosthetic leg and wore hearings aids. Prior to being murdered by her step-mother she had been abused by her. Five year-old April Jones from Wales (BBC News Wales, 2012), who had cerebral palsy, was murdered in 2012. As with the Baker case there was sensational media coverage of her murder. In 2011 Cynara Ali's (Toronto Star, 2012) mother was charged with criminal negligence causing death in Canada. In 2008 in England Naomi Hill, a young girl with mild cerebral palsy was killed by her mother (BBC News, 2008) and there was quite extensive coverage of the trial and failings within the child welfare system in that matter as well. Eight year-old Julie Cirella (Huffington Post, 2012) who also had cerebral palsy was murdered by her mother in 2011 in the United States in a case strangely dubbed 'the M&M case' due to Julie's nut allergy. There are other such recent cases involving girls with severe disabilities.

A question that arises is whether there is a prurient interest or a fetishization[11] of the problems these girls encounter and whether this phenomenon provides a partial explanation for the sort of media coverage engendered by the murders of girls who have severe disabilities. Goodley and Runswick-Cole (2011) comment that:

> Broadly speaking a fetish is that which we (mis) believe will sate our desires. In capitalist societies, the process of fetishisation describes the values that we inhere in objects or commodities that they do not intrinsically have. Fetishistic culture imbues objects with value (from sculpted pecs, to expensive wine, the latest iPhone, to pathological children and uncivilized nations). The disabled body is also a fetishised object, onto which are conferred a whole host of (unconscious) values that sate a variety of values. (Goodley and Runswick-Cole, 2011, p. 612)

There are at times sex crime components to these cases. Sex crimes in these instances involve the interlocking vulnerable statuses of (a) childhood, (b) female, and (c) disabled. Reports of them draw close attention to the personhood of the girls involved not only in the context of the law but in larger society as well. These reports imply that there is something uncommon about the

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[11] Jessica Eisen in reviewing an early draft asked insightfully whether this was a possibility.

hostility directed towards these children, and yet violence (Goodley and Runswick-Cole, 2011) and sexual abuse (Sullivan and Knutson, 2000) against children with disabilities is perpetrated at higher levels than it is against non-disabled children and is not all that uncommon at all. There is then an unhelpful mythology that surrounds the personhood of girls with severe disabilities.

Given all of the above, one is necessarily curious about the relationship between the way in which the law treats these girls and the matter of their embodiment. If as Shildrick (2002) claims, the adult female body is perceived to be 'morphologically dubious' then arguably the body of the severely disabled girl would be even more so. Morphologically dubious beings do run into problems with legal personality, a notion Naffine (2010) gets at when she states it is often asked in law whether X or Y have "*the right characteristics* to be thought of as a legal person" (author emphasis). In considering the question of what the "right" characteristics might be, Naffine (2010) points out that at one time being female was not one of them and Shildrick (2002) elegantly states that:

> The relationship of the monstrous body as other, and the feminine body as other, both implicitly in relation to the masculine subject, is a highly complex one, but what it does seem to speak to is a deep abiding unease with female embodiment, and indeed to the corporeal in general…" (p. 29)

I suggest that law's interpreters are not immune from this 'unease' with female embodiment (Shildrick, 2002) when the matter is one involving a girl who is severely disabled. One cannot help but wonder whether this has had a role to play in the way that some interpreters of the law have "downplayed" the personhood of girls who live with severe disability in Canada and elsewhere. It doesn't seem unreasonable to assert that this is what happened in the second trial regarding the murder of Tracy Latimer. The factum of the Disabled Women's Network in the *Latimer* case asserted that:

> [T]his Court should not see Tracy Latimer only in terms of her disabilities. Her status as a human being must be paramount. Her disability cannot be used as a justification for departing from fundamental constitutional values. **She was a person first and that fact must not be obscured by the detail of her medical circumstance** (*author emphasis*).

The Body of a Girl

In her essay “Throwing Like a Girl” Murdoch (1994) comments that an essential part of being female entails “living with the ever present possibility that one will be gazed upon as a mere body, as shape and flesh that presents itself as the potential object of another subject’s intentions and manipulations…” (p. 154). This is something that resonates particularly with the experiences of girls living with severe disabilities as will be seen in the examples I raise below respecting bodily integrity. Murdoch (1994) comments that women live with the on-going threat of the invasion of their bodies and states that the most extreme form of bodily invasion is rape. Girls who are disabled, however, live with higher levels of sexual abuse than non-disabled girls (Freeman, 2000; Sobsey and Doe, 1991) and the other threats and actualities of bodily invasion they also live with are many and varied. Meekosha (1998) points out that “… violence against women with disabilities, violations against their bodies, murder, medical mutilation and enforced sterilization and abortion” are realities for many women with disabilities. Many of these things however actually begin in girlhood. They are as such significant social justice issues for girls. In *“Manipulating growth and puberty in those with severe disability: When it is justified?”* Butler and Beadle (2007) make it apparent that paediatricians are realizing that in the context of invasive procedures, their first allegiance is to the child, and as a result are questioning certain kinds of medical practices that have been performed with impunity on girls with severe disabilities[12].

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[12] And still are.

Law's Girl

Naffine (2009) states that:

> One of the most basic and penetrating ways in which law reaches into our social and private lives is by means of its concept of the legal person.1) By granting legal rights and duties, law establishes legal relations, and it also personifies: that is, it turns us into legal persons or legal actors, right holders and duty bearers, beings who are therefore capable of acting and relating in law. 2) Concomitantly, by denying legal rights and duties, law effectively "unpersons". 3) that which is deemed incapable of bearing any rights and duties is so thoroughly disabled at law that it is generally thought of as property. Animals, for example, essentially fall into this category. (Naffine, 2011, n.p.)

Davis (1996) explains that to come to grips with the present day situation for persons with disabilities one must refer back to the Poor Laws of Great Britain. He explains that there were five categories in the poor law regulations and that children, the sick and 'defectives' were three of these categories. He further explains that at the time these laws were amended in 1834 most of the persons in the poor house were orphaned children, the sick and the disabled. The Poor Laws are part of the history of the child, of the disabled person and of the sick person today. According to Davis (1996) these laws, (originating in 1601 with *Old Poor Law*) provided a schematic that still exists for the administration of persons with disabilities (in modern form). Davis (1996) also informs us that this model set the stage for the disability legislation in place today. The model treated persons with disabilities as social problems (Davis, 1996), which is something Green (2007) points out is true today where children with disabilities are concerned. In the poor law model, those who were the deserving poor were forced to accept charity *in exchange for rights* (understood today by critical disability scholars as 'the charity model' of disability). This history shows another way in which people can become separated from their rights.

Civil Disabilities

There was a time when individuals convicted of crimes had their civil rights[13] lifted from them at the point of their conviction (Saunders, 1970). This loss of civil rights was termed 'civil death.' This lifting of rights was also at times referred to as the imposition by the state of "civil disabilities" (Blacks Law Dictionary, 1979). Rioux (2003) has also addressed the matter of 'civil disabilities' and has done so in relation to the citizenship rights of persons with disabilities whom she states experience civil disabilities once they have given over authority "to those who claim the scientific knowledge to determine capacity and competence. This differentiation includes the power to suspend citizenship rights…". I am claiming that there is case law that suggests there is another manner of civil disability, one that makes its appearance on occasion when severely disabled girls assert their rights in court or other decision making bodies of influence, and their person is treated as though it is "less than" that of the other persons.

Of the doctrine of civil disabilities it was stated in a 1932 issue of *The Harvard Law Review* that (Saunders, 1970) :

> With living men regarded as dead, dead men returning to life, and the same man considered alive for one purpose but dead for another, the realm of legal fiction acquires a touch of the supernatural under the paradoxical doctrine of civil death.

This note highlights another way in which the law has the ability to construct and deconstruct the person, shifting her or him into and out of the space where the state has a set of firm obligations towards the person. Manza and Uggen (2004) comment that at one time civil death was such a precarious status that it often ended with injury or death since convicts could be killed without threat of criminal sanction. One effect of civil death then was that a convicted individual was no

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[13] Actual rights they were stripped of varied across time and place as noted by Manza and Uggen (2004).

longer a protected personality[14] at law. I raise the matter of civil disabilities at law because this matter demonstrates that less than full support from the state puts one in a dangerous place and because my reflections here have led me to consider that this is similar to what some girls with severe disabilities have experienced in some settings. The state-run school is but one example of a place where girls with disabilities experience violence as Goodley and Runswick-Cole (2011) demonstrate in their research.

While it may seem a stretch to compare the status of a girl with a severe disability with that of a convict's unique status of civil disability, one need only consider the name of one disability rights group, "Not Dead Yet" to the see reason for the comparison. For some persons with disabilities the line between life and death is not clearly drawn and their perspective is that they are being positioned legally and ethically towards the end of a continuum. To support this belief, examples in the Canadian context of killings of children with severe disabilities that were not prosecuted are raised, and the treatment of these cases by the justice system has become controversial in the disability community as a result. The Council of Canadians with Disabilities (CCD) protested the fact that charges were not laid in the deaths of several children living with severe disabilities (CCD, 1996, 1999, 2001). CCD also formally protested the treatment at law of twelve-year old Tracy Latimer in Saskatchewan (CCD, 2008) by intervening in the litigation along with other groups. Tracy Latimer was not treated in the court of public opinion (C-News, 2010) or by the sentencing judge as a non-disabled girl would have been. CCD has stated in an

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[14] Personality is a legal term of art about which a great deal has been written and debated. Lawson in his 1957 piece "The creative use of legal concepts" comments for example that "there is an enormous juristic literature about the legal personality" (p. 916). For other examples see Stone, O. (1979). Canadian women as legal persons – How Alberta combined judicial, executive and legislative powers to win full legal personality for all Canadian women – The Jubilee of Henrietta Muir Edwards and Others v. Attorney-General for Canada decided October 18, 1929. Alberta Law Review (331) 331. L.L. Fuller (1930). Legal Fictions. *Illinois Law Review (25)*4; Geldart, W.M. (1911). Legal Personality. *Lawyer's Quarterly Review, 90.*; Maitland, P. (1905) Moral Personality and Legal Personality. *Journal of the Society of Comparative Legislation (6)*2, 192-200.

article entitled *The Toll Mounts: Another Child Killed* that “with the killing of another child with a disability, CCD must emphasize the importance of the Supreme Court statement on denunciation…” The point being made by CCD is that in law the severely disabled child must count. *Not counting* is something Naffine (2009) asserts as central where there is less robust legal personality. When ‘not counting’ takes place in legal decisions, such as with the under-prosecution of matters concerning these girls in the manner expressed by CCD, I suggest they cease in effect to have full personhood (they lack full legal personality in that setting) with the result that they inhabit a place where they have insufficient protection.

Barnes (1992) describes a 1990s charity poster that was used to raise funds and to educate the general public by what was formerly called The Spastics Society (UK) (now called SCOPE). He explains that this poster showed two babies and carried the text “One has cerebral palsy. The other has full human rights”. The poster also listed one child’s functional impairments and the text below proclaimed “*in an ideal world she’d turn to the law. In reality she’ll turn to The Spastics Society*”. This poster deserves mention because it is an example of the linking of disability status through image and words to an apparent lack of legal status for a child (a female baby with a disability in fact). It is not therefore an original observation here that children (boys and girls) with more severe disabilities have found themselves situated *as if* outside the law, as this poster makes clear. It has been long understood to be the case within disability rights circles, and as noted above it has its source in The Poor Laws. To summarize my point here though, the opposite of civil rights might be framed as civil wrongs, and the title of Shakespeare’s (2006) classic disability studies text “Disability Rights and Wrongs” alludes to this very notion. Where girls with severe disabilities are concerned the lack of clarity[15] about

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[15] This has been made apparent for example in recent cases in Canada that were similar in nature to the American Baby Does cases in the 1980s. See CTV News Staff (March 13, 2009) Couple Sues Hospital

their rights may operate in some domains as a form of civil disability, where, like convicts in the past, girls at birth or later are stripped of their rights, as the charity poster (Barnes 1992) suggests.

The *Latimer* case, which I address below, demonstrates that parents may on rare occasion pose a risk to severely disabled children[16]. Some parents, however, allege that it is health policies that place their disabled daughter's lives in jeopardy. They point to practices such as the placement of 'do-not-resuscitate' orders on the hospital charts of infants with severe disabilities who are very ill (Farlow, 2009). These parents assert that policies concerning infants who are severely disabled or who are very sick remain under-scrutinized and they argue that what is needed is clarification of the rights of children with severe conditions and/or disabilities and their parents in decision making. This raises different sorts of questions than those Naffine (2009) asks, such as *what is the law?* and *is the law clear and if not, why not?* The clarification these parents seek is at the intersection of medical notions of personhood and the legal notion of personhood. A girl who fails to 'fit' as medicine's person[17] and who does not 'count' with a law's[18] interpreter[19] may be a girl at risk[20][21]. With respect to not fitting, a further question one

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for Keeping Sick Baby Alive. Retrieved on July 4, 2012 from http://www.ctvnews.ca/couple-sues-hospital-for-keeping-sick-baby-alive-1.379178 and also CBC News Edmonton, March 11, 2012 Baby Isiah Dies in Edmonton Hospital. Retrieved on July 7, 2012 from http://www.cbc.ca/news/canada/edmonton/story/2010/03/11/edmonton-baby-isaiah-court-appearance-cancelled.html

[16] My position is that the vast majority of parents advocate and support their children with severe disabilities in a highly dedicated manner.

[17] The question of personhood is in part what the trilogy of Baby Doe cases in the United States was about. See *The C. Everett Koop Papers: Congenital Birth Defects and the Medical Rights of Children: The "Baby Doe" Controversy* at http://profiles.nlm.nih.gov/ps/retrieve/Narrative/QQ/p-nid/86

[18] An ethics committee for example

[19] Law's interpreters as I use the term here can be anyone making decisions of the kind made by ethics committee's which interpret the rights of the child, tribunals and courts but also includes lawyers who try through their legal advocacy to influence judge's decisions. They too interpret the law.

[20] A baby who is anencephalic is a more obvious example.

might consider is a societal one - whether the severely disabled girl, in not having taken on the various modalities of feminine comportment which Murdoch (1990) claims are central to being a girl, who may not look like 'typical' girls look, is seen to have transgressed dominant norms of *what it is to be a girl*. Does this line of reflection engage Naffine's (2009) question as to *who is law's person?* I believe it does. Naffine (2009) states that when lawyers use the term 'person' they try to empty the word of moral meaning and invoke only the person to whom the law gives the means to hold rights and duties. She states that it is through the concept of the person that law defines who will count. The nature of personification in law is, she argues, a measure of social thought which, she notes, allows for the enforcement of such thought. According to Naffine (2009) law reflects as well as articulates those ideas in the society which expresses who is of value.

The deaths of Canadian girls Samantha Martin and Annie Farlow raised questions for their mothers that arose at the intersections of institutional[22] treatment, severe disability, female status and death. Children with severe disabilities as a group usually lack autonomy as minors and many lack agency as well. It is for these reasons that they require others to advocate for them. However, it is apparent that they also need advocates to advance their rights because, as I have noted, in domains critical to their continued presence, their rights are not always clear. It is simply not the case that persons with disabilities receive equal treatment and it is for this reason

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[21] Ypinazaar (2003) states that "Disability as tragedy is the taken-for-granted social construct reflected perhaps in the nurses' perception of 'personhood'" in the case she was discussing. She refers to the medical model as the personal tragedy model. She states that "the concept of personhood is in tension with disability particularly as it relates to intensive medical intervention of a baby named with disabilities." (p.197).

[22] Institutions in these cases were institutions specifically set up for the welfare of children with additional needs.

that Articles 12, 13 and 14 were placed in the Convention of the Rights of Persons with Disabilities[23].

Samantha Martin’s death was eventually investigated by an Alberta Fatality Inquiry (CBC October 19, 2012), while Annie Farlow’s[24] death was investigated through a Coroner's Paediatric Death Review Committee[25] (Farlow, 2012). We know what we know about the deaths of these two girls only as a result of the concerns their mothers raised publicly. In both cases these girls’ deaths would not have come under this sort of scrutiny *but for* their mothers’ insistent demands of government. Such investigations offer an important way for us to learn more about policies and practices that involve children with severe disabilities that we may or may not agree with and importantly to permit questions and recommendations regarding their legal rights.

The Child Of Civic Value

Hudson (2011) comments that Nazi ideology held that some persons had more “civic value” than others. He tells the story of Richard Kretschmar, the father of a severely disabled baby, writing to Hitler to request that his son be killed because of his severe disabilities[26]. Hitler consented and ordered a physician to kill the baby. Hudson (2011) states that this act of filicide is credited with establishing state policy towards disabled children, stating that “[M]otivated by the Kretschmar case, and with the country now at war, the Nazis seized the opportunity to legislate

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[23] Article 12 Equal recognition before the law; Article 13 Access to Justice; Article 14 Liberty and security of the person. Consideration of these Articles in the setting of childhood is different than in the setting of adulthood.

[24] Some of the facts of these cases are offered below.

[25] The role of the Coroner in this process is restricted to making sure that all pertinent questions related to a death are answered and if necessary, to make recommendations to prevent a similar occurrence. In Annie Farlow’s matter the involved hospital made many recommendations and the coroner added one (Farlow, 2012).

[26] Some have suggested that this parent was encouraged to send this letter to Hitler by other Nazis. Others, like Hudson (2011), refer to this as a chance letter.

for a more consistent approach for similar children" (Hudson, 2011). According to some, the killing of this child was used to test the water respecting euthanasia policies. Shortly after the death of Gerhard a 'Reich Ministry decree' was enacted and their disabled child euthanasia program commenced (United States Holocaust Museum Encyclopedia, nd, np). Children with disabilities in Germany experienced a form of civil death by virtue of the fact that laws were made ensuring that they were not protected as citizens and could and should be killed. This history represents a gross example of children with disabilities being cast outside the law through an act of commission. However, I suggest that certain acts of omission may effectively cast them out as well. Smith (2011) on the same topic states that "once we decide that some human beings have lesser value than other human beings, it ceases to become a question so much of whether we will oppress, discriminate, or even, kill them, but *what form* the invidiousness will take" (np)[27] and who will be included in the group. One form in which a *lesser value* reveals itself is when the state fails to ensure that *all* children have realized their full and equal legal rights across domains. As noted above, children with severe disabilities do not enjoy the same legal rights as non-disabled children. Moreover, there are questions that arise with respect to their rights that crop up before children's hospital ethics boards, in neonatal intensive care units, in child welfare courts, in criminal cases, in schools and elsewhere that call out for further attention.

"Girls We Love For What They Are"[28]

The question of who is of value and who is not is one that raises issues disability advocates feel passionate about and especially where it concerns support to infants with severe

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[27] See http://www.nationalreview.com/human-exceptionalism/326061/euthanasia-mass-grave-grim-reminder-human-exceptionalism-necessary-never

[28] The words of Johann Wolfgang Von Goethe. The full quote is "Girls we love for what they are; young men for what they promise to be".

disabilities.[29] The case of Annie Farlow offers an example of the kind of disputes that arise in this setting. Annie Farlow was born with a congenital condition in 2005. When Annie became ill at two and a half months of age she was transferred to a children's hospital in a large metropolitan area for further treatment. There she died under circumstances that left her parents querying the health policy governing the circumstances of her death[30]. In one of several articles she wrote after her daughter's death "The decision to accept disability: One family's perspective" Farlow (2008) stated:

> The coroner and his committee noted issues about our daughter's final admission. An effective 'do not resuscitate' order had been placed on her chart, yet this had not been discussed with us. … The infant with predicted disabilities lives the most fragile of human lives. The fate of our child rested in the hands of the physicians and health care providers. … Some would say that helping a child like Annie live longer by offering more aggressive medical interventions would be unfair and burdensome to the child and family, and an irresponsible use of limited societal resources. We believe that parental involvement and consent in treatment decisions are acutely important issues. When they are overlooked systemically and without cause, there is a necessity to reflect on the implications. (np[31])

Quebec paediatrician and bioethicist Dr. Annie Janvier stated in relation to Annie's case that "There's a perception in the medical community[32] that the lives of these children are not worth living..."[33] Following upon Naffine's (2009) line of questioning and the comments of Farlow (2008) one must ask *for whom* are the lives of these children not worth their living? Farlow, Janvier and Wilfond (2012) demonstrate through their qualitative research that lives like Annie's

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[29] One need only look to the work of Peter Singer and the controversy surrounding his ideas about the value of severely disabled infants.

[30] It is important to note here that the formal inquiry into this matter found no wrong doing on the part of Annie's physicians or on the part of the hospital. The discussion here is one about gaps in policy and not one about culpability of physicians.

[31] http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2532897/

[32] "The medical community" is not all of one mind. However, Ypinazaar (2003) observes that nurses perceptions of the "personhood" of babies in their care influences treatment choices and she references Becker and Grunwald, 2000, p. 66 for this position.

[33] Though obviously there are physicians who strongly disagree with the evaluation of the life of a child with a severe disability as having a lower value.

are of value to parents and siblings. Freeman (2011) in "Children at the edge of life: Parents, doctors, and children's rights" explores this area asserting it is one that calls for far more consideration. The parents of Samantha Martin, an Alberta girl born with a rare medical and physical disability, were urged to place their daughter in specialized foster care when she was very young. After a decade living in a specialized foster care setting Samantha was returned to the care of her parents where she died of a heart condition a few months later. During her time in foster care Samantha's school had filed incident reports and the foster care home was investigated (Sarrazin, 2012). Six years after her death (CBC-Edmonton, 2012) the Alberta government released its results of their inquiry into her death. As with the unnamed girl with multiple disabilities who was the subject of the B.C. Representative for Children and Youth report *Isolated and Invisible: When children with special needs are seen but not seen* (2011), Samantha had allegedly experienced institutional neglect. Where the British Columbia girl with severe disabilities was discovered alive in a fly infested trailer lying beside her disabled mother's corpse, in Samantha's case many of the problems with the alleged inappropriate levels of care went unnoticed until after her death. What these examples demonstrate is that girls with severe disabilities are at times treated as though they are *less than* other persons, and girls with severe disabilities are at times *perceived* as being less valuable to their families and as less entitled to live with their families.

Mary Ellen Turpell-Lafond, the B.C. Representative for Children and Youth noted in the conclusion of her report (2011) regarding the unnamed girl who was the subject of that investigation "*we have laws and practices that support the dignity of life and fair treatment for all. Despite all of this, this child led a life that was impoverished, in every sense of that word*". The question that arises is if, as this Report asserts, *there are laws*, why is it is it that severely disabled girls do not always benefit from them? In Samantha’s case recommendations from the Fatality Inquiry matched other recommendations that have been made elsewhere under similar circumstances. Basic social work practice guidelines regarding children with severe disabilities have been made before (Morris, 1999; Oliver, 2006; NSPCC, 2003) in a variety of publications for over a decade now. The recommendations made in the 2011 BC Representative’s Report had essentially and comprehensively already covered off what the later 2012 Alberta Fatality Inquiry recommended respecting social work and medical service oversight for children in the system who have severe disabilities. It is already well understood what the shortcomings are. The problem is mobilizing resources for an undervalued population whom society does not always value and whom the law does not always protect.

Cases Involving Girls With Disabilities

There have been several cases in Canada (and elsewhere) involving the legal rights of children with more severe disabilities. In some of these cases, parents and their children have sought to advance the rights of these children through litigation. There have been for example a series of cases concerning the rights of children with autism to services and funding. These have been nicely set out and discussed by Bell and Petrick (2010) in “Autism and the Law: Themes in Recent Litigation.” There has been a large body of legal literature about the *Latimer* case (see for example Sampson, 2001; Sneiderman, 1997; Sneiderman, 2001; Kaiser, 2001). The title of Lepofsky’s (2001-2) “Murder is still a murder when the victim is a child with a disability” is one that addresses the fact that a child with a disability is a victim *under the law*. The Latimer case, as noted above, was about a girl who lived with a severe disability and who was murdered by her father. The case continues to engender heated debate in Canada in many different media fora.

Indeed, this twenty- year old murder case involving a girl who was severely disabled may be one of the most controversial and most talked about cases in Canadian legal history. There are reasons for that. One of them is that this case drew attention to the matter of Tracy's apparently contested legal rights as a person not to be murdered.

The reality is that many girls with disabilities have been constructed as less than robust persons in Canadian history. In earlier times girls with disabilities lived with legislated civil disabilities of a very particular kind and certain rights were formally stripped from them. For example, in Alberta in 1959 Leilani Muir was admitted to an institution for "mental defectives" at the age of eleven. There she was sterilized under *The Sexual Sterilization Act, 1928*. Many years later, in Muir *v.* The Queen in the right of Alberta (1996), Ms. Muir as an adult, sued the Alberta government for the way in which that province had treated her. Her doing so provided an opportunity for reflection on matters pertaining to her personhood and the personhood of others like her. Madam Justice Veit stated in that case:

> … the province wrongfully surgically sterilized Ms. Muir ... the particular type of confinement of which Ms. Muir was a victim resulted in **many travesties to her young person:** loss of liberty, loss of reputation, humiliation and disgrace, pain and suffering, loss of enjoyment of life, loss of normal developmental experiences, **loss of civil rights**, loss of contact with family and friends, [and] subjection to institutional discipline (author emphasis).

One might argue that the case of Leilani Muir is of only vague historical significance to the discussion here because women's rights and the rights of persons with disabilities have come far since the 1950s. However there is evidence that similar practices continue in spite of this lawsuit and others addressing similar issues[34] in North America.

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[34] See the Eve Case in Canada as well. E. (Mrs.) v. Eve [1986] 2 S.C.R. 388

Ashley X was an American girl with profound disabilities who between 2004 and 2006 and starting at the age of six went through the surgical removal of her reproductive organs and tissue and also a series of growth reduction treatments. Her case became controversial when her paediatricians published their account of her "treatment" (Gunther and Diekema, 2006) and when her parents put up a blog about their "pillow angel". Ashley's parents sought to prevent her from passing through puberty and to keep her small in size so she could be cared for more easily and apparently to safeguard her from sexual abuse. It does not appear that their intentions were to harm her. In the pursuit of their treatment agenda for Ashley, neither her family nor her paediatricians obtained a court order prior to the removal of her tissue, organs or the ending of her growth potential. In Ashley's case, the matter did go before the children's hospital ethics committee where she was being treated. One might have expected, given Ashley's vulnerable status as a girl with a severe disability, that the ethics committee there would have required her family to obtain a court order to have these surgeries performed, but that did not happen. A hospital ethics committee would (I argue) fall under Naffine's (2009) 'interpreters of the law' as such committees routinely make decisions that have legal implications. It was decided by the ethics committee that the added layer of judicial scrutiny of the treatment plan for Ashley was not indicated in her case. That, in and of itself, was a harm that signified difficulty with the status of this girl, who had the right to have the matter heard by a judge (Ouelette, 2008). With hindsight being 20-20, it was apparent that the ethics committee was ill equipped to deal with this matter. What was it about Ashley X that was different than a non-disabled six-year old girl? What is it that Ashley X shares with some other girls who, like her, live with severe disabilities? I suggest that one thing Ashley shares with other girls like her is the lack of a firm boundary around her body.

I suggest two things arise also with regard to this matter, one moral and one legal. Where those in positions of trust fail to act in the interests of the girl or indeed go against her interests, one can argue that they have breached their fiduciary duty towards her. That is a legal issue. I came across just a few articles that address fiduciary duties towards girls within the context of the family (Scott and Scott, 1995; Hall, 2002; Grace and Vella, 1994) and child protection more generally (Hall, 2000). On the other hand, the lack of firm boundaries is also a moral issue in the sense that personal privacy with respect to a girl’s body and its functions, something that is ‘a given’ for many, may be intruded upon by others including by support workers, and family. This becomes problematic to the extent that personal support is unwanted by the girl who experiences violation of her body. An example of this would be sexual touching while assisting with bathing; being rough while assisting with personal care; running interference when efforts are made to report these activities to authority figures.

These sorts of bodily violations may be complicated where a girl is perceived as lacking capacity to give or withhold consent to assistance or treatment. She may be deemed incapable of providing testimony in the event that she might wish to bring a claim for more serious violations of her body, or not be believed. The situation becomes more challenging when those the girl trusts are the perpetrators.

In considering the personhood of the girl with severe disabilities, questions that may arise, if even unconsciously, are those such as ‘will this girl ever become a mother?’ and more to the point ‘do we want her to?’ Nancy Mairs (2008), who explores these (and other) themes related to sexuality in *Sex and the Gimpy Girl*, stated that “The parents of a congenitally disabled daughter may rear her to believe that she will never enter a sexually intimate relationship like the one that they enjoy themselves” (p. 9)

As noted, Naffine (2009) suggests that it is not uncommon for jurists to ask about whether natural beings have the necessary attributes to constitute legal persons (though that is not exactly what is going on here, it is similar to it). Had Ashley X not been severely disabled it is a virtual certainty her parents would not have requested the above noted procedures, the paediatricians would not have agreed to perform them and the ethics committee would have asserted the legal requirement of a court order, something the court undoubtedly would not have provided. Ouelette (2008) points out plainly that a court order was legally required for the physicians to perform Ashley's hysterectomy and therefore she says *the law failed Ashley X.* In light of this legal 'oversight' one is obliged to consider Naffine's (2009) central question *who is law for?* In this case it was not for Ashley.

Naffine (2009) explains that the legalist's view is that one's legal nature ought not to be confused with one's other personality or other nature beyond the confines of the law. It has been stated in "The creative use of legal concepts" that legal personification "facilitates calculation in law" (Lawson, 1957). All that is required to be a legal person, accordingly, is that judge, jurists, legislators and others "should decide to treat it as a subject of rights or other legal relations" (Lawson, 1957). Yet, as we have seen, Naffine (2009) argues that jurists and others are influenced by other people's persons (by the metaphysical persons she refers to). Where the abstraction of the legal personality is reputedly valueless, the metaphysical personalities she describes clearly are not. They are heavily value-weighted in fact in favour of one perspective on 'human-ness' or another. Naffine (2009) also argues that in spite of the legal fiction of law's person, the matter of personality calls for comments as to the meaning of 'person' from fields such as medicine, philosophy, theology etc. who wish to understand what it means to be 'a being' (2009). The latter is something she states (2003) is an "irritant" to adjudicators who must deal with law's persons in the setting of both confusion and division in the jurisprudence. Others, like Freeman (2011), state that circumstances that arise, for example for severely disabled babies, have "tested both ethicists and courts". The ways in which courts and ethicists have been tested are (I argue) in the area of personhood. We see evidence of just this in the Shefer (below) and Latimer cases.

As mentioned earlier, Naffine (2009) states that the domains of rationalism, religionism and naturalism inform legal decisions about legal personality – regarding who can be what and when and why. She further claims these ways of considering legal and moral existence are powerful because "They supply the rationale for making 'x' count in law, but not 'y'". In setting out various aspects of law's person Naffine (2009) offers the example of the deceased person holding on to features of their legal personality after death. As many are aware, a deceased person may, through their will or by holding a donor card, maintain the right to control the use of their bodily tissue post mortem. The legal person exercising this right, she explains, is one with full rights and who is described as being the rational adult actor. Theirs is a civil right that a court will ordinarily uphold. It is interesting in light of this aspect of legal personhood to go on to consider that there are cases where severely disabled girls (like Leilani Muir and Ashley X[35]) have been seen to hold no rights whatsoever over their own tissue *while they are living*. This comparison demonstrates that a dead person may have greater rights than a living person over his or her own body and this comparison is one which I argue calls us to ask why that is and what it means about different bodies and the legal personalities that inhabit or do not inhabit them. It ties into embodiment and the valued and devalued body. A deceased embodiment may have more

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[35] According to the Blog, pillowangel.org, Ashley's parents communicate with a dozen other parents from around the world who have had this treatment performed on their sons and daughters as well. There is research that shows that parents routinely "prioritize personhood over disability" in their children. See Ypinazaar (2003).

ability to see an agreement through than a living one, which challenges the notion that one must be born and not yet dead to have the rights that vest in the legal person.

What is clear is that there is some evidence that in certain domains, rights pertaining to a disabled girl's body are vague[36]. The girls under discussion at times appear to hold ambiguous legal status when certain kinds of decisions were made regarding them. Naffine (2009) further comments that humans tend to have ambiguous legal statuses more often at "the margins of life" (2009). Drawing on her insights into law's person is useful as they can help us see more clearly the places where girls with disabilities have been left unprotected. Moreover her ideas about law's person are also useful because they indicate that unless one clearly 'fits' as "law's person" one may find oneself having trouble with the law, in particular where laws interpreters are concerned. Naffine (2003) points out for example that "…there are pockets of case law in which 'the person' forms the subject of sustained discussion because the entity in question appears to have problematic status." For Naffine the difficulty is with "the denial of legal personality to entities that are candidates for moral status, because they are sentient beings …". When advocates argue for the rights of a girl who is not seen to have a full rights, who may be described as being at the margins of life, who is not seen to share the same envisaged future of other girls (like marriage or motherhood[37]) it is a fact that the case for personhood may have to be made in an effort to influence law's interpreters that the girl before them is in fact a person, even though that is a given. Not only that, but that she is a person who meets certain required criteria to count, to matter in a given set of legal circumstances. This raises important issues such

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[36] In fact one need not actually be disabled to be treated as disentitled - one need only be perceived to be disabled. Later in life Leilani Muir was administered an intelligence test and she performed within a so-called "normal" range. This suggests that the perception of being "less than" other girls is enough to dangerously jeopardize a girl.

[37] This explicit gendered vision of a girl's future is included here because I believe there is a hidden subtext in some decisions that are taken regarding girls who live with disabilities that are more severe.

as whether girls with severe disabilities do in fact meet the criteria for personhood that is held in the minds of various interpreters of the law from different domains and whether the notion of personhood is a suitable basis on which to base moral and legal decisions especially in light of its failure to highly vulnerable girls.

Girlhood With Personhood

The *making-a-case for personhood* for a girl with a severe disability was seen in the criminal case of R. v. Latimer (1997)[38]. Robert Latimer admitted to having killed Tracy, he said, to alleviate her pain. He was charged with her murder, convicted, and sentenced to the mandatory ten-year period without parole. The conviction was over turned on appeal. After a second trial Latimer was again found guilty, however a motion was brought with regard to his sentencing which sought a declaration that it would be a violation of Latimer's rights under s. 12 of the Charter of Rights and Freedoms (which asserts that everyone has the right not to be subjected to any cruel and unusual treatment or punishment) were he to be given the mandatory minimum ten year sentence. Justice Noble, the interpreter of the law in this instance, granted a constitutional exemption to Robert Latimer, thus allowing him an out from the mandatory minimum sentence for this crime. This Judge's comments reflected the court's view of the personality of Robert Latimer much more robustly than it did of Tracy, the girl with a disability. None of the usual stigma that ordinarily accrues to a child murderer seemed evident in the comments of this judge who opined:

> It is my judgment that even though the offence of murder is the gravest of all crimes in our law that the circumstances established by the evidence as to why and how he committed this compassionate act of homicide **when taken together with his personal characteristics…** his conviction does not warrant the imposition of the ten-year

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[38] CANLII 11319 (SK QB).

> minimum sentence because it would be unjust, unfair and far too excessive (author’s emphasis).

The Latimer case, in my view offers an example of what Goodley and Runswick-Cole (2011) assert, namely that “disabled children are brought together as a specific cultural site: the dumping ground for the projection of non-disabled society’s fears of illness, frailty, incapacity and mortality” (referencing Shakespeare, 1997).

The Factum of the coalition of intervenors (CCD, 1998) at the Saskatchewan Court of Appeal on the other hand set out that:

> The Coalition respectfully submits that this Court should not see Tracy Latimer only in terms of her disabilities. Her status as a human being must be paramount. Her disability cannot be used as a justification from departing from fundamental constitutional values. **She was a person first and that fact must not be obscured by the detail of her medical problems** (CCD, 1998, np). (author’s emphasis).

This same Factum noted (quoting Lepofsky and Bickenback) that many consider “Those "suffering" from these conditions deserve pity, for they have been robbed of the true fullness of life; **they are not whole persons**.”[39]

I imagine the “persons” being referenced in this factum are the same metaphysical persons Naffine describes (the rationalist, the religionist and the naturalist persons). I also imagine that the goal in this factum was to remind the court as to the presence of the legal personality of Tracy Latimer to ensure that she, as a legal entity, received full legal protection under the Criminal Code. To that end, these intervenors emphasized the issue of her personhood.

Legal personality is a legal term of art. Personhood on the other hand is a term used widely by people generally and is a word seen used in several of the factums filed with the court

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[39] Their quotation is from Lepofsky, M.D. and Bickenbach, J.E. in "Equality Rights and the Physically Handicapped" in Bayefsky and Eberts, Equality Rights and The Canadian Charter of Rights and Freedoms. Toronto: Carswell, 1985.

in the Latimer matter. I believe the intervenors were trying to assert Tracy's legal personality through the use of this word because they perceived that to be under direct threat and could see moreover that hers lacked traction. As I note elsewhere it has been stated (Landsman, 2003) that disability diminishes personhood. That was precisely the concern of those attempting to convince the court in Latimer not to forget that Tracy was a legal person. Of course, they employed a variety of approaches to do that, relying on metaphysical persons, just as Naffine (2009) suggests takes place in such settings. Tracy's legal personality was something they perceived to be undermined by the focus on her disability. The Latimer case went to the Supreme Court of Canada and in 2001 that court held that Robert Latimer's Charter rights had not been infringed by the imposition of a ten-year prison sentence. In the Factum of the Intervenors at the Supreme Court of Canada, *The Evangelical Fellowship of Canada, Christian Medical and Dental Society and Physicians for Life* in an effort to sway the court as to the legal rights of the severely disabled girl asserted that:

> The legal issues in this appeal must be examined against the backdrop of a threshold issue - **was Tracy Latimer a "person" in the eyes of the law** and cloaked with the dignity and protection which surrounds a person; **or, was she something less than a person** whose killing should not attract the existing penalties of Canadian criminal law? If one acknowledges that Tracy Latimer was a person, then this appeal should fail (author's emphasis).

This Factum tackles directly the matter of Tracy's perceived absent personality by this group at Robert Latimer's sentencing. One could argue that this is an example of a non-legalist's (religious) person bumping up against the lower court's construction of Tracy, suggesting perhaps she had been un-personified (to use Naffine's words). The treatment of Robert Latimer by the motions court lends weight to Naffine's (2009) comment that it is arguably implied in law that the law is designed for some beings and *made in their image*. Latimer's otherwise law-abiding personality appeared to hold more sway somehow with the motions judge than did that of his deceased daughter. That Robert Latimer had been a conscientious rights and duty holder up to this point in time was set out clearly by the court. The problem for Tracy Latimer was not only her personality as it appeared to this court. Her personality was problematic in the court of public opinion as well (C-News, 2012). Tracy, it would appear, was found lacking not only as law's child but as society's child as well.

The examples above are drawn from North America. Courts elsewhere have considered the rights of girls with severe disabilities as well. In Israel in 1993 the Supreme Court (sitting as the Court of Appeal) addressed the law as it applied to a two-year old girl called Yael Shafer who had Tay-Sachs disease. Yael died in 1990 but her matter went on to be judicially considered even though it was moot. The issue before the court was whether Yael could refuse treatment[40]. Yael's case is reported in a fascinating 147- page decision that addresses many issues that tie in with legal personality. The *obiter dicta* in this case reflects also the perspective Naffine (2003, 2009) takes in her work on legal personality regarding the need for a 'fit' between law's person and the being whose matter is before law's interpreters and whether or not the person before the court 'counts' as a person. As the quotation from *The Harvard Law Review* at the beginning of this discussion explained so well, the "realm of legal fiction" may be invoked at law to

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[40] In Shafer *v.* State of Israel [1993] CA 506/88 the mother applied to the District Court for declaratory relief to allow her daughter to refuse treatment when she became gravely ill. The application stated that "[Yael] through her mother and natural guardian, is entitled, if and when her state of health deteriorates …to refuse said treatments against her will". Interesting is that the opening remarks in this judgment from Supreme Court Vice-President M. Elon is the statement that "Against your will you are created, and against your will you are born, against your will you live and against your will you die". This is a religious perspective and very early in this case it is apparent that the religionists person whom Naffine mentions in her work is present in judicial deliberations and very much bumping up against other considerations by this court's consideration of Yael as law's person. A medical perspective might be to comment that in medicine you are created (IVF for example) by medicine you are born (caesarian section) and in medicine you die (DNS orders, removal from life support and the like). This case also brings to light the metaphysical person Naffine (2009) refers to in her analyses.

characterize persons as either living or dead according to law’s purpose. The court in this Israeli case stated that:

> We have dealt in detail with the various arguments raised by counsel for both sides in the course of our discussion of the position of Jewish Law and American Law on this subject. **Certainly, Dr. Lerman’s definition of Yael’s condition as ‘comparable to a dead person’ cannot be reconciled with the values of a Jewish and democratic State.** I am amazed how that this can be said of Yael, who responds by crying when uncomfortable like any other child her age, whose father sits by her bed day after day and plays music for her... (p. 138) (author emphasis).

In considering the testimony of Dr. Lerman in the litigation above, one might consider Naffine’s (2011) question as to “whether the law is trying to match or capture the nature or quality of life when it personifies” or whether in fact it is “engaged in a quite distinct legal pursuit - coining its own basic conceptual unit- the person – for its own legal purposes?” Yael, it would appear, lived and died in a legal tug of war where the nature of her personality at law was contested. She was even construed in the courtroom as being dead when she was in fact very much alive.

Conclusion

This paper began with a questioning of who the law is for, drawing from the work of Naffine (2009) and asked whether the apparent perceived lack in the area of personhood in a girl with a severe disability is a thing of the past or is still with us today. The intersections of child, female and disabled status somehow places a person at a disadvantage with the law, at least in the cases I have referred to. Theories of critical disabilities or of feminism do not yet have the answers to many of the questions raised in this discussion. My aim was not to tie together each of the sections discussed, nor to present a hypothesis or even a single story line about girls with severe disabilities. I explored the treatment of the personhood of the girl living with severe disabilities with reference to some historical practices as well as through reference to decisions concerning girls with disabilities in law and ethics. To my knowledge diverse contemplations on the topic of legal personality and personhood of girls (and boys) with severe disabilities is still relatively uncharted territory. Naffine’s work sets out to demonstrate the way in culture and therefore law ‘reflects’ *who* society values. Her questioning of who is law’s person and who is law for, while having a different focus than my inquiry, nevertheless helped me to contemplate reasons why girls with severe disabilities may find they lack legal traction with the law being less responsive towards them than to a non-disabled girl. Naffine’s questions regarding who law is for force us to confront, as she herself points out, that the law may not be for everyone.

In closing, girls with severe disabilities are girls first, even though we can see from the steps taken and arguments made, some legal cases that concern them do not always reflect this. In raising questions about the “problem” of personhood that seems to exist for some girls with disabilities and the implications of that, I hope my ideas here will engender further reflection by others in critical disability studies and elsewhere.

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