

EXPLORING INTERSEX WELLNESS:  
A SOCIAL WORK APPROACH

by

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## **Abstract**

This thesis explores some of the themes and issues that social workers may wish to consider when investigating and addressing matters pertaining to wellness in individuals with sex-variances. Foundational literature includes writings by John Money, the Chicago Consensus, and the clinical guidelines of the Intersex Society of North America. A three pillars model is introduced as a potential means for fostering better understanding and diversity in relation to sex, gender, and sexuality. Semi-structured interviews surrounding wellness are conducted with four individuals who have sex-variances. Interview results are analysed using Interpretative Phenomenological Analysis. Recommendations are put forth in a manner designed to allow social workers to work collaboratively with individuals who have sex-variances and their families, as well as with other medical and health professionals who provide services thereof. The analyses and recommendations presented in this thesis are situated within a context of evidence-based anti-oppressive practice.

### **List of Abbreviations Used**

ADAM:	A.D.A.M. Medical Encyclopedia
AIS:	Androgen Insensitivity Syndrome
APA:	American Psychological Association
CAH:	Congenital Adrenal Hyperplasia
CASW:	Canadian Association of Social Workers
CBC:	Canadian Broadcast Corporation
CDC:	Centers for Disease Control
DSD:	Differences/Disorders of Sex Development
FAO:	Food and Agricultural Organization of the United Nations
IPA:	Interpretative Phenomenological Analysis
ISNA:	Intersex Society of North America
LANB:	Legislative Assembly of New Brunswick
NASW:	National Association of Social Workers
NIH:	National Institutes of Health
WHO:	World Health Organization

## **Glossary**

Androgen Insensitivity Syndrome: condition where a person who has one X and one Y chromosome is resistant to androgens.

<http://www.nlm.nih.gov/medlineplus/ency/article/001180.htm>

Congenital Adrenal Hyperplasia: condition where the body cannot produce an enzyme the adrenal gland needs to make the hormones cortisol and aldosterone.

<http://www.nlm.nih.gov/medlineplus/ency/article/000411.htm>

Dexamethasone: a corticosteroid, similar to a natural hormone produced by the adrenal glands, often used to replace this chemical when the body does not make enough.

<http://www.nlm.nih.gov/medlineplus/druginfo/meds/a682792.html>

Hypospadias: condition where the opening of the urethra is on the underside of the penis.

<http://www.nlm.nih.gov/medlineplus/ency/article/001286.htm>

## **Chapter 1: Introduction**

This thesis will investigate wellness among individuals with sex-variances through the use of exploratory qualitative interviews. Recommendations based on these interviews will be made in order to facilitate future research and interventions surrounding sex-variances. For the purpose of this thesis, sex-variances refer to congenital arrangements of genotypic and phenotypic sex attributes that fall outside of the archetypical parameters for both female and male. The key points here are that sex-variances are present at birth and involve the body.

Recently, some studies have produced findings surrounding wellness outcomes in individuals with sex-variances, but there is still a dearth of knowledge that needs to be addressed. In their study involving 37 individuals with a diverse range of sex-variances, Schützmann, Brinkmann, Schacht, & Richter-Appelt (2009) found "seventeen (46%) participants reported lifetime suicidal thoughts" (p. 29) and that participants "were markedly more distressed ... compared to non-clinical norm data" (p. 30). This study indicates that psychological wellness outcomes for individuals with sex-variances are often poorer than for sex-normative individuals. Social work research can explore further what social changes are necessary to improve the quality of life of individuals with sex-variance, and contribute to the development of interventions which foster beneficial wellness outcomes rather than impeding them.

In this thesis, I engage in an exploratory study that utilizes the qualitative research methodology of phenomenology. In order to translate the study findings into recommendations appropriate to the social work profession, I employ a

phenomenological approach called Interpretative Phenomenological Analysis, or IPA. The framework for IPA is described in Smith, Flowers, & Larkin (2009):

IPA is a qualitative research approach committed to an examination of how people make sense of their major life experiences ... IPA also recognizes that access to experience is always dependent on what participants tell us about that experience, and that the researcher then needs to interpret that account from the participant in order to understand their experience. (p. 1-3).

Fade (2004) further writes, "IPA is phenomenological in that it seeks an insider perspective on the lived experiences of individuals, and interpretative in that it acknowledges the researcher's personal beliefs and standpoint and embraces the view that understanding requires interpretation" (p. 648). In using IPA, researchers act much like art gallery docents, using their own knowledge to go beyond the static finished pieces and into the dynamic minds of the artists themselves.

While empirical scientific knowledge surrounding sex-variances has grown substantially over the past several years, the ways in which people with sex-variances are treated, especially in terms of how their wellness is understood and addressed by medical and health professionals, has yet to experience such a profound evolution. There are many ways to define wellness. Many contemporary definitions are expressly holistic and pertain to quality of life in terms of various biological, psychological and sociological facets. These include emotional, workplace, social, behavioral, environmental, intellectual, interpersonal, and further aspects of wellness (CDC, 2013; LANB, 2000; Shalock, 2004; Swarbrick, 2006).

Because there are multiple facets involved in wellness, it is necessarily holistic, and needs to be addressed on both individual and collective levels. Each individual and group shapes their understandings of wellness based on their circumstances and experiences/histories. Social work, with its focus on a *person-in-environment* approach to practice, is readily able to work within holistic contexts. I note that wellness, as a holistic concept, is ideally suited to be addressed by multidisciplinary teams. Such teams, consisting of health and medical professionals who provide services collaboratively, are more productive, more economical, and able to provide a higher overall quality of service than are an assortment of lone practitioners who work in isolation of one another.

Through using a balanced approach to wellness that addresses both detriments and benefits, health and medical professionals become able to not only combat illness, but also to promote quality of life. As social workers, one aspect of wellness that we may routinely address in our professional lives is social wellness. Roscoe (2009) describes social wellness as "the movement towards balance and integration of the interaction between the individual, society, and nature" (p. 218). Using a balanced approach to wellness here, we may both combat social exclusion in the form of stigmatization, and foster social inclusion in the form of acceptance (Prilleltensky, 2010). As will be seen later on, people with sex-variances may benefit from social work that employs a balanced and holistic approach to wellness. At this time, I will introduce some nomenclatural concerns surrounding sex-variances.

Sex-variances are called *Disorders of Sex Development (DSD)* by the medical and other health professions. Many individuals and organizations have opted to use the terminology *Differences of Sex Development*, thus maintaining consistency in the use of

the DSD initialism, but in a way that does not serve to stigmatize. Until very recently, sex-variance conditions were referred to as *intersex(uality)*; while this term is now obsolete, the fact that it is still widely used and easily recognized was my rationale for using it in both the title of this thesis and in the study recruitment text.

A number of years ago, sex-variance conditions were called *(pseudo)hermaphroditism*, but such terminology is now outmoded to the point of being considered offensive. Lee, Houk, Ahmed, & Hughes (2006) state that "terms such as 'intersex,' 'pseudohermaphroditism,' 'hermaphroditism,' 'sex reversal,' and gender-based diagnostic labels are particularly controversial. These terms are perceived as potentially pejorative by patients and can be confusing to practitioners and parents alike" (p. e488). Oddly, these authors replace what they deem to be pejorative terminology with terminology that is equally problematic, namely Disorders of Sex Development.

Although Disorders of Sex Development is currently popular among the medical and health professions, I argue that it merely reiterates the emphasis on pathology that is already provided within the name of each sex-variance condition. Specific examples of such conditions include Androgen Insensitivity Syndrome or AIS (NIH, 2008, para. 1) and Congenital Adrenal Hyperplasia or CAH (ADAM, 2012, para. 2, etc.). Words like syndrome and congenital are succinct, identifying sex-variances as medical conditions without stigmatizing, thus removing the need for a problematic umbrella term like disorder. I recommend that medical and health professionals use the names of specific sex-variance conditions whenever possible, as these names offer maximum precision with minimum stigmatization. Furthermore, these condition names satiate the semantic needs of the involved professions, including medicine, nursing, and social work, as well

as the insurance industry, funders, and policymakers. I chose to use *sex-variance* as an umbrella term in this work, because it is uncontroversial and inoffensive, while at the same time simple and precise. I suspect that complete consensus surrounding terminology here is improbable, and that it is likely to continue evolving over time.

There are no comprehensive statistics on the rates of sex-variances, only approximations that vary immensely from one source to another. This lack of statistical data is compounded by the fact that there are several sex-variance conditions. NIH (2008a) reports that "complete androgen insensitivity syndrome affects 2 to 5 per 100,000 people who are genetically [chromosomally] male. Partial androgen insensitivity is thought to be at least as common as complete androgen insensitivity" (para. 4). The National Institutes of Health online medical library reports that "about 1 in 10,000 to 18,000 children are born with congenital adrenal hyperplasia" (ADAM, 2012, para. 1). Given these rates, it is reasonable to suggest that sex-variance conditions are uncommon, affecting fewer than one percent of the population.

Sex refers to genotypic and phenotypic traits that coalesce as a complex, interrelated array of biological attributes comprising the dimorphic categories of female and male. Such attributes include genitals, gonads, secondary characteristics, karyotype, hormonal composition, neural composition (Ngun, Ghahramani, Sánchez, Bocklandt, & Vilain, 2011), skeletal composition (Gilsanz, Kovanlikaya, Costin, Roe, Sayre, & Kaufman, 1997), and possibly more. It is important to note that although a number of sex attributes can be artificially modified to an extent, no means has been discovered to systemically manipulate the entire array of sex attributes, such that the notion of (re)assigning sex is a misnomer at best. It is inconceivable here to posit sex strictly as

genitals, on account of sex being highly complex, so it is equally inconceivable to hold that sex can be shaped simply through genital surgery.

Sex, although pertaining to biological attributes that are quite well-understood by contemporary science, is elaborate and complex, extending beyond the purely biological into the social, political and cultural spheres. As Judith Butler, an acclaimed scholar of feminist theory and queer theory who is particularly influential in the areas of gender and sexuality, rhetorically asks in her 1990 book *Gender Trouble*, "are the ostensibly natural facts of sex discursively produced by various scientific discourses in the service of other political and social interests?" (p. 7). Bioethicist Alice Dreger (2010) relates such political and social interests to sex-variances in saying that "sex is complicated enough that we have to admit nature doesn't draw the line for us between male and female or between male and intersex or female and intersex, we actually draw that line on nature." (6:14-6:28). These two quotes serve to shatter the illusion of sex as a purely objective standard. I maintain that while sex does indeed consist of those genotypic and phenotypic traits mentioned above, understandings of these traits are driven by sociopolitical factors that are external to the sexed body.

Sex is as much a product of society as it is of biology (Greenberg, 1999; Knouse, 2005; Geller, 2008). This is made clear, for example, in regulations surrounding participation in women's athletics by athletes who have, or who are suspected of having, sex-variances. Gandert, Bae, Woerner, & Meece (2012) indicate that "to an extent, the designation of sex into male and female categories is likely an oversimplification ... there is a percentage of the population that does not fit neatly into the categories of male or female" (392). They then go on to say:

Any future decision to include or exclude intersex athletes from competition will make a statement about the acceptable normal range of variation for a female athlete. It may not be possible to precisely define the bounds of what is and what is not female. One method of defining the normal range of variation is by gauging whether an intersex competitor's abilities exceed those of a biologically typical female ... Defining an acceptable range of variation for female athletes in a manner that does not take into account athletic ability poses a great danger of prejudice and overreliance on outmoded sex stereotypes. (399)

Even though sporting officials cannot redefine sex and sex attributes in the same authoritative way as medical professionals, such officials do have the capacity to fine-tune the parameters surrounding sex in sporting. This can allow athletics to keep up with changes to understandings and norms in the larger society. In discussing some of the perceived competitive advantages of woman athletes with sex-variances in relation to Y chromosomes and testosterone, Adair (2011) writes:

If testosterone really does give men such an advantage, then intersex athletes who have Y chromosomes but do not benefit from testosterone are unfairly considered male, such as athletes with gonadal dysgenesis (Swyer Syndrome) who possess a Y chromosome but no testes that produce testosterone. Female athletes with androgen [in]sensitivity possess a Y chromosome but, because they cannot synthesize the testosterone in their body, are at a *competitive disadvantage* when competing against traditional XX women, who, while having lower amounts of testosterone, can metabolize and use that testosterone to their advantage.

Normative values surrounding women involved in competitive athleticism are challenged by those athletes who have sex-variances. Inclusiveness toward such athletes necessarily involves changes to the parameters surrounding sex, thus evidencing sex as being at least partly shaped by social construction. As has been demonstrated above, the parameters surrounding female and male expand and contract to comply with various external forces, such as changes in scientific understandings or sociopolitical constraints. Contemporary understandings inform us that the sexes are not mutually exclusive and overlap considerably. If we can incorporate these overlaps into our conceptualizations of sex, and begin to think of the sexes as something other than binary opposites, then we can truly start to interpret sex-variances as differences rather than as flaws deserving of condemnation.

The societal factors surrounding sex offer a segue into the matter of gender. Gender is a vast, complex, and interrelated web of biologically, environmentally, and socioculturally-rooted behavioral and physical traits that comprise femininity and masculinity, from which emerges the constructs of girl/woman and boy/man respectively. Milton Diamond (2000), professor of anatomy and reproductive biology at the University of Hawaii, elaborates on the evolution of gender as a concept:

General usage of the term gender began in the late 1960s and 1970s, increasingly appearing in the professional literature of the social sciences. The term came to serve a useful purpose in distinguishing those aspects of life that were more easily attributed or understood to be of social rather than biological origin ... Males and females, as biological entities, were accepted as essentially similar cross-culturally but men and women, by virtue of the multitude of different roles they

played in diversified societies, were not so easily catalogued. These anthropological life-style differences came to be accepted as social and cultural constructs. Indeed, the terms sex and gender came, for most investigators, to signify and reify these different areas of consideration; sex would refer to biological traits while gender would refer to social/cultural ones. (p. 47)

Today, numerous individuals and organizations, including many outside of feminist circles, recognize a distinction between sex and gender. For example, the World Health Organization (WHO) (2013) states:

"Sex" refers to the biological and physiological characteristics that define men and women. "Gender" refers to the socially constructed roles, behaviours, activities, and attributes that a given society considers appropriate for men and women. To put it another way: "Male" and "female" are sex categories, while "masculine" and "feminine" are gender categories. Aspects of sex will not vary substantially between different human societies, while aspects of gender may vary greatly.

Despite sex and gender being conceptually divergent, in practical terms the division is largely a semantic matter, for sex and gender are now understood as too intricately fused to be neatly separated. Nicholson (1994) elaborates:

While many of us assume [gender] has a clear and commonly understood meaning, it is actually used in at least two very different and, indeed, somewhat contradictory ways. On the one hand, *gender* was developed and is still often used as a contrasting term to *sex*, to depict that which is socially constructed as opposed to that which is biologically given. On this usage, *gender* is typically

thought to refer to personality traits and behavior in distinction from the body. Here, *gender* and *sex* are understood as distinct. On the other hand, *gender* has increasingly become used to refer to any social construction having to do with the male/female distinction, including those constructions that separate "female" bodies from "male" bodies. This latter usage emerged when many came to realize that society not only shapes personality and behavior, it also shapes the ways in which the body appears. But if the body is itself always seen through social interpretation, then sex is not something that is separate from gender but is, rather, that which is subsumable under it (p. 80).

The body is always social, interpreted through an ever-changing historical and social lens and corresponding shifts in meaning (Brown, 2007). For Foucault (1980), the body is always in the "grip" of cultural practices. Further, Butler (1990) states "perhaps this construct called 'sex' is as culturally constructed as gender; indeed, perhaps it was already gender, with the consequence that the distinction between sex and gender turns out to be no distinction at all" (p. 7).

Although conflating sex and gender may be standard practice in relation to *normative sex/gender* manifestations, it is nonetheless important to distinguish *sex-variance* from *gender-variance*, both of which contravene normative parameters. If *sex-variance* and *gender-variance* are conflated, then variant genitals, which normative ideology views as an anatomical instability, are necessarily seen as creating an instability of the psyche (in that said normative ideology views all forms of *gender-variance* as psychological instability). When variant genitals are erroneously thought to be a causal antecedent of psychological instability, then it becomes easy to demand normalization in

the form of cosmetic surgery. This fallacy is found in the work of Money & Ehrhardt (1996):

When an hermaphroditic child with uncorrected genital ambiguity manifests early in life the signs of differentiating an ambiguous gender identity, or one contradictory of the assigned sex, then it is probable that the child has been responding developmentally to the evidence of the ambiguous and uncorrected sex organs (p. 16).

This proposition and others by John Money have definitively shaped the approach taken towards sex-variances by the medical and health professions, and by society as a whole, particularly in terms of imposing non-consensual cosmetic genital surgeries on children.

Even if it might be said that certain physical and social environments are apt to cause gender atypicalities in some individuals with sex-variances, the cause here can in no way be reduced to variant genitals. Further, any potential for such variances cannot be undone through cosmetic genital surgery. Sex is complex, too much so to be contingent upon genital appearance, a single incidental consequence of a much larger picture. One of the central assertions in this thesis is that non-consensual cosmetic genital surgery is not only a futile effort that serves only to exasperate already distressing circumstances, but constitutes an unacceptable violation of self-determination and informed consent. Further, such surgeries are often devastating to the individuals on whom they are performed. Dispelling the idea that variant genitals equate to psychological instability, a task which can be accomplished in part through properly distinguishing between sex-variances and gender-variances, may help to abate the ideological drive behind these surgeries.

Besides being invasive, and constituting a blatant violation of both self-determination and informed consent, non-consensual cosmetic genital surgery can, and often does, cause impairments to sexuality. Sexuality refers not only to matters surrounding sexual function, but also to sexual self-concept, which Winter (1988) defines as "an individual's evaluation of his or her own sexual feelings and actions" (p. 123), and to expressions and desires stemming from it. A component of sexual self-concept is sexual orientation, which APA (2012) defines as "the sex of those to whom one is sexually and romantically attracted" (p. 11). To be sure, a definition of sexuality needs to include *asexuality* if it is to be comprehensive. Regarding asexuality, Bogaert (2006) states:

[The] definition of asexuality concerns a lack of sexual attraction to either sex and not necessarily a lack of sexual behavior with either sex ... It would also not necessarily mean that these individuals have no desire for sexual stimulation ... It would also not necessarily mean that these individuals do not have any capacity for physical arousal ... Finally, it would not necessarily mean that these individuals do not have romantic/affectionate attractions for others ... (p. 241-242)

Thus asexuals, even those with a complete absence of sexual attraction, do indeed possess a sexual self-concept and a sexual orientation.

I have thus far discussed sex, gender and sexuality. Further, I have indicated that there are dominant norms surrounding these concepts. Such norms form an ideological system known as *heteronormativity*. Wieringa (2012) elaborates:

Heteronormativity refers to a system in which sexual conduct and kinship relations are organised in such a way that a specific form of heterosexuality becomes the culturally accepted “natural” order. Thus, gender relations, biological sex, sexuality, gender identity and normative gender roles are aligned in such a way that a dominant view of sexual relations is produced (p. 515).

I offer here my own operational definition of heteronormativity that encompasses sex, gender and sexuality: Heteronormativity is a systemic ideology which holds that there are exactly two mutually exclusive sexes, female and male; that these sexes are the causal antecedents of exactly two corresponding mutually exclusive genders, feminine/woman and masculine/man respectively; and that heterosexuality is the only sexual orientation which is normal and natural.

Heteronormativity is an important matter in sex-variance discourse, and in this thesis, as it is the institution that drives the practice of non-consensual interventions on children with sex-variances, including the often devastating practice of non-consensual cosmetic genital surgery. If heteronormative ideology can be abated, or at least subdued, then the ills that accompany it will subsequently wane accordingly.

Unfortunately, overcoming heteronormativity is no easy endeavour, as it necessarily involves widespread resistance, given the magnitude, complexity and pervasiveness of the institution. Current sites of resistance against heteronormativity include such schools of thought as feminism, queer theory, intersectionality, and other critical approaches. Such resistance does not necessarily need to diametrically oppose heteronormative positions in order to be rightfully called resistance, only to seek to expand the existing parameters beyond the confines of the heteronormative, so as to be

more inclusive. As the appearance of body itself is indeed a social product, greater inclusion of bodies with sex-variances requires a paradigm shift that discards binary essentialism in favour of broader conceptualizations.

On their own, sex-variances, gender-variances, and sexuality-variances may appear to be divergent matters. However, heteronormative ideology lumps them all together and collectively marginalizes them in such a way that the threat to heteronormativity that they pose might likewise be combined into a concerted endeavour of resistance. This is not to say that the involved factions would necessarily form one big happy unified front, only that this would be an efficient means to resist heteronormativity. To this end, I have adopted the *three pillars* model, encompassing diversity of sex, gender and sexuality. Each of these factors interconnect with the others in such a way that the biology, identity, behavior and desires of any individual all function interdependently.

The three pillars model is not a novel concept, but builds upon developments that have occurred over the past several years. I recall in the 1980s when the gay and lesbian community (usually referenced at that point simply as the gay community) became the LGB community (lesbian, gay, and bisexual), which then became the LGBT community when transgender was included in the 1990s. Today, the initialism has expanded to LGBTTT2IQQAA (lesbian, gay, bisexual, transgender, transsexual, transvestite, two-spirit, intersex, queer, questioning, asexual, and ally). The three pillars model provides a means to conceptualize the essence of these developments.

It is important here to be mindful of intersectionality, which allows individuals to be understood in terms of a nexus of intersecting factors, each acting as a source of both

"oppression and opportunity" (Shields, 2008, p. 302). Regarding intersectionality, and of particular importance to anti-oppressive researchers and practitioners, Parent, DeBlaere & Moradi (2013) write:

Intersectionality perspectives, which share as a common thread the recognition of multiple interlocking identities that are defined in terms of relative sociocultural power and privilege and shape people's individual and collective identities and experiences, constitute a vital step forward in research across multiple domains of inquiry (p. 640).

Sex-variances fit into the intersectionality discourse in a number of ways. Firstly, sex-variances fit alongside other non-heteronormative groupings as being subordinated through heteronormative ideology. This is the basis for the three pillars model. While sex-variances are not gender-variances and are not variances of sexuality, all three are nonetheless simultaneously marginalized through heteronormative ideology. This is a site of oppression. Here, the three pillars model represents a particular aspect of the larger intersectionality perspective. Through narrowing the scope of intersectionality to three interconnected parts, the three pillars model maintains clarity by preventing variances of sex, gender and sexuality from becoming less-discernible amid a sea of diversity. This is not to say that the three pillars cannot be melded with additional intersections where needed, only that the three pillars model makes sex, gender, and sexuality easier to comprehend and analyse. This may allow for the development of more robust approaches in confronting heteronormativity.

Secondly, sex-variances threaten heteronormative conceptions of sex through which other non-heteronormative groupings are socially located. For example, gay,

lesbian and bisexual are socially located vis-à-vis straight. Sex-variances threaten all of these groupings by calling into question the binary conceptualization of sex. Without female and male as comprehensive binary categories, there is no clear understanding of what straight, gay, lesbian and bisexual mean. If someone is not "properly" female or male according to heteronormative standards, then they cannot be "properly" straight, gay, lesbian, or bisexual according to the same standards. As the roots of sex-variances penetrate all the way down to the genomic foundations of the affected individuals, surgical modification can only conceal the most superficial manifestations of sex-variances and can thus not eradicate the threat they pose to heteronormative foundations. In order to accommodate for sex-variances, the conceptualization of sex is forced to expand beyond the heteronormative. This is a site of opportunity.

The three pillars model critiques the homogenous lumping of sex, gender, and sexuality by heteronormative ideology, and does so by explicitly positioning sex, gender and sexuality as three individual – yet not exclusive – pillars. In the three pillars model, sex, gender, and sexuality function neither like three distinct corners of a triangle, nor like a singular mass. Instead, the pillars partially overlap so as to form a tripartite Venn diagram of sorts. The arbitrary lumping together of sex, gender, and sexuality by heteronormative ideology makes it appear, falsely, that variances of sex, gender, and sexuality are one and the same. I have demonstrated above that this is clearly not true. Here, it is necessary for progressive and anti-oppressive scholars, researchers, and activists, to be mindful that sex-variances are not an LGBT subset. In their article about the teaching of sex-variance issues as part of feminist and LGBT-based curricula, Koyama & Weasel (2002) write:

Beyond the assumption that a greater visibility will eventually lead to the liberation of a marginalized group, a carryover from lesbian, gay, bisexual, and transgender (LGBT) politics, there seems to be little thought around how advocating for intersex people might take a different form or require a different set of priorities than advocating for LGBT communities ... While LGBT communities can certainly provide forums for addressing intersex issues, conflating or collapsing intersexuality into LGBT agendas fails to acknowledge the specific and urgent issues facing intersex people ... Recognize that the intersex movement may have priorities and strategies beyond those of the gay and lesbian or transgender movements. Do not automatically treat intersex issues simply as an extension of LGBT issues, or intersex people as a subgroup within LGBT communities (172-175).

Even though medicine has improved in recent years in terms of respect for the agency and rights of individuals with sex-variances, as evidenced by Lee et al. (2006), who lay out up-to-date guidelines for medical professionals treating individuals with sex-variances, the medical model still fails to meet the ethical standards of the social work profession, which places explicit emphasis on self-determination and informed consent (CASW, 2005, p. 4; NASW, 2008, Ethical Principles section, para. 4). While Lee et al. (2006) tend to be generally more progressive and cover more facets of life than the approaches of yesteryear, offering such statements as "quality of life encompasses falling in love, dating, attraction, ability to develop intimate relationships, sexual functioning, and the opportunity to marry and raise children, regardless of biological indicators of sex" (p. e493) and "long-term outcome in DSD should include external and internal

genital phenotype, physical health including fertility, sexual function, and social and psychosexual adjustment, mental health, quality of life, and social participation" (p. e493), they offer little in the way of specific strategies. This may be an opportune site for social work involvement, given the profession's emphasis on holistic biopsychosocial approaches.

I think it would be beneficial if social work had approaches of its own surrounding the investigation of, and recommendations of interventions for, sex-variance conditions – approaches that reflect social work ethics and its scope of practice. Such approaches may allow social workers to use evidence-based methods that uphold the self-determination and informed consent of individuals with sex-variances, and may well encourage the medical profession to follow suit. Evidence-based methods here would include avant-garde professional expertise and empirical findings, but would place emphasis on the lived experiences of individuals with sex-variance conditions, thus allowing for better understandings of which approaches have or have not been successful in bringing about improvements to wellness.

Persistent mindfulness and diligence are of the essence here, as sex-variance diagnoses are most commonly made, and treatment(s) commenced, while the individuals in question are still in their infancy or early childhood, long before they are able to fully comprehend or appreciate the nature of their medical situations or of the treatment options (or lack thereof) that may be pursued. Social workers here may be called upon to mediate accords between caregivers and the involved medical and health professionals, accords that could be centered around the rights and wellness needs of the children in question. As with any approach involving children, it is crucial to keep in mind that they

are each individual human beings – notwithstanding their youthful naivety and vulnerability. They need to be protected from intrusive medical involvement. Social workers who fail to exercise due diligence in maintaining critical awareness here may find themselves becoming complicit in violating the rights of children with sex-variances.

When working with children with sex variances, social workers may wish to help children and their families learn how to identify, confront, and overcome shame and stigma. In working with adolescents and adults with sex variances, social workers may also wish to help those seeking their services to overcome shame and stigma. In addition, social workers may wish to put those seeking their services in touch with mental health and addiction supports as the need arises. It would also be beneficial for social workers who provide services to children and adolescents with sex-variances to weigh in favor of these children's future needs and desires when considering what the best treatment options may be. This is a site where evidence-based social work research may be used to inform all of the involved medical and health practitioners of the most empowering and least intrusive interventions available. While social workers frequently serve in the forefront of care and advocacy for people with sex-variances and their caregivers, such endeavours have tended to be led by physicians and shaped by the medical model. Here, a shift to multidisciplinary perspectives, which includes the perspectives of anti-oppressive social workers, could prove invaluable.

A further goal of this thesis is to craft recommendations designed to facilitate evidence-based, anti-oppressive social work practice involving individuals with sex-variances. By evidence-based practice, I mean the "process in which the practitioner combines well-researched interventions with clinical experience and ethics, and client

preferences and culture to guide and inform the delivery of treatments and services" (Social Work Policy Institute, 2010). By anti-oppressive social work practice, I mean the "form of social work practice which addresses social divisions and structural inequalities in the work that is done with 'clients' (users) or workers" (Dominelli, 1993, p. 24). While evidence-based practice and anti-oppressive practice can be used in isolation of one another, I expressly mean them to operate concurrently here. It is hoped that through such practices, there can emerge marked quality of life enhancements for people with sex-variances, especially children (who are unable to fully appreciate the realities of their sex-variances and are thus unable to fully consent to interventions thereof).

In the next chapter, I will review some of the influences in the evolution of sex-variance discourse, beginning with sexologist John Money, then the Chicago Consensus, and lastly the Clinical Guidelines of the Intersex Society of North America (ISNA). Following that, I describe the research methodology used in the study for this thesis. Afterwards, I describe research findings, and then move on to my interpretations and recommendations. Lastly, I conclude with some final observations and discussion points.

## **Chapter 2: Evolution of Sex-Variance Discourse**

In making determinations of where social work and other health and medical professions might go in terms of understandings, research, and recommendations surrounding sex-variances, it is important to be aware of both past and contemporary understandings and approaches. To recap, I will provide an overview of John Money, then the Chicago Consensus, and lastly the ISNA Clinical Guidelines. Money takes a social-centred approach in which socialization and upbringing play a key role in shaping the human experience. The Chicago Consensus is based in the empirically-centred approach of the medical profession. The ISNA guidelines are grounded in a patient-centred approach in which the needs and voices of patients/clients/service recipients are afforded precedence. While these three literature sources are by no means the entirety of sex-variance discourse, they are representative of where modern sex-variance discourse has been, where it is now, and the approaches that may develop in the years to follow.

### **2.1 John Money**

Throughout the latter half of the 20th century, and even into the early 21st century, the clinical approach to sex-variance focussed largely on (hetero)normative genitals and gender identity, with sexologist John Money as a key authority. Creighton & Minto (2001) cite Money as stating "that to achieve a stable gender identity a child must have unambiguous genitalia and unequivocal parental assurance of the chosen gender" (p. 1265). However, Money & Ehrhardt (1996) write:

... A premature excess of body masculinization does not inexorably preordain that a hermaphroditic [sic] child living as a girl will differentiate either an ambivalent or masculine gender identity. The variable that holds the balance of

power would seem to be the consistency of the experiences of being reared as feminine, especially in the early years. (p. 16).

It is apparent that while Money considered the presence of atypical genitalia to increase the likelihood of a child developing an atypical or ambivalent gender identity, he also held that socialization is a more powerful influence than anatomical appearance alone.

Money also stated that "there is, in the brain, a biology of learning and remembering" (Money & Ehrhardt, 1996, p. xi), indicating he believed that experiential factors are involved in shaping an individual's cerebral makeup. This position is supported by some contemporary studies (e.g., Heidelise, Duffy, McAnulty, Rivkin, Vajapeyam, Mulkern, Warfield, Huppi, Butler, Conneman, Fischer, & Eichenwald, 2004; May, 2011; Noble, Houston, Kan, & Sowell, 2012). It is clear Money understood that our biological selves intersect and interact with our social selves and with our environments. In fact, Money & Ehrhard (1996) state that "the basic proposition should be not a dichotomization of genetics and environment, but their interaction" (Money & Ehrhardt, 1996, p. 1). In the end, Money abandoned this understanding and instead came to social-constructionist conclusions.

Money is perhaps best known for his account of the David Reimer case, oft-dubbed as the 'John/Joan case'. Reimer, who born as a boy in 1965, was raised as a girl (on the advisement of Money himself) after a routine circumcision procedure went catastrophically awry. This case was marketed as compelling evidence that early genital surgery and parental decisiveness in terms of gender-rearing could allow a child to conform to the identity and roles associated with either normative gender, and was used as an exemplar for treating children with sex-variances (i.e., for promoting non-

consensual cosmetic genital surgery). However, two problems arise here: firstly, Reimer's situation was entirely the result of surgical ineptitude and was thus markedly different from the situations of children with sex-variances, and secondly, Money's account of Reimer was flatly inaccurate.

After telling of a childhood in which David Reimer became increasingly masculine, and defiant towards being raised as a girl, his mother Janet and his twin brother Brian revealed that as he "was reaching puberty, it became increasingly clear the experiment was not working ... At the same time, the Reimers were under pressure from Money to take the final step: allow surgeons to create a vagina." (CBC News Online, 2004). It was at this point that David Reimer "threatened to commit suicide if he was forced to make another trip to Baltimore to see Money. That's when his father broke down and told him everything" (CBC News Online, 2004). After three suicide attempts, "Reimer left his Brenda identity behind. He cut his hair and started wearing male clothing again. He changed his name to David" (CBC News Online, 2004). Sadly, David Reimer committed suicide on May 4, 2004.

Since Money's rise to popularity in the 1950s and 1960s, new perspectives have shaped the sex-variance field. The social constructionism of Money's heyday has since waned in favor of a more evidence-based approach. This approach, while still using expert testimony, favors empiricism over paternalism. The Chicago Consensus, which I shall discuss next, uses an evidence-based approach — albeit one that is not expressly complemented by an anti-oppressive approach.

## 2.2 Chicago Consensus

John Money's dominance in the sphere of sex-variance has been largely replaced by 21st century discourse, and a new chapter began when, according to Sandberg (2006):

Working groups, comprised of 50 international experts, members of the Lawson Wilkins Pediatric Endocrine Society (LWPES) and the European Society for Paediatric Endocrinology (ESPE), convened in Chicago in October 2005 to formulate a consensus document derived from an evidence-based literature review (para. 1).

The consensus statement resulting from this conference, namely Lee et al. (2006), is commonly known as the Chicago Consensus. It is a leading treatise on addressing sex-variances (referred to in the consensus statement as DSD). While the Chicago Consensus is designed for use by the medical profession, the material covered in it is applicable to all health professions, including social work. As with all paradigms, the one presented through the Chicago Consensus must be continually deconstructed and remolded so as to keep up with changes in understandings and approaches, a task that social workers may wish to prepare themselves for through the use of ongoing critical investigations. For example, social workers may wish to investigate the effectiveness of peer support for individuals with sex-variances (an intervention explicitly advocated by Lee et al., 2006, pp. e490-e497), perhaps examining such issues as how to network peer supports in order to enhance their effectiveness, or ways in which individuals can be connected to peer supports that best suit their own particular needs.

Lee et al. (2006) take a more live-and-let-live approach to non-heteronormativity in individuals with sex-variances than did their predecessors, making such statements as:

It is important to emphasize the separability of sex-typical behavior, sexual orientation, and gender identity. Thus, homosexual orientation (relative to sex of rearing) or strong cross-sex interest in an individual with DSD is not an indication of incorrect gender assignment (p. e489).

Lee et al. (2006) also state: "Atypical gender-role behavior is more common in children with DSD than in the general population but should not be taken as an indicator for gender reassignment" (p. e492). In terms of dissatisfaction with gender of rearing, Lee et al. (2006) indicate that the phenomenon "occurs more frequently in individuals with DSD than in the general population but is difficult to predict from karyotype, prenatal androgen exposure, degree of genital virilization, or assigned gender" (p. e489) and they recommend that "in affected children and adolescents who report significant gender dysphoria, a comprehensive psychological evaluation and an opportunity to explore feelings about gender with a qualified clinician is required over a period of time" (p. e492-e493). Lee et al. (2006) further state that:

Much remains to be clarified about the determinants of gender identity in DSD. Future studies require representative sampling to carefully conceptualize and measure gender identity, recognizing that there are multiple determinants to consider, and gender identity may change into adulthood. In terms of psychological management, studies are needed to evaluate the effectiveness of information management with regard to timing and content (p. e496).

Given that the social work profession is well-equipped to conduct research into the matter of gender (dis)satisfaction, this may be an ideal site for the profession to enrich the sex-variance discourse.

Lee et al. admit that "although clinical practice may focus on gender and genital appearance as key outcomes, stigma and experiences associated with having a DSD (both within and outside the medical environment) are more salient issues for many affected people" (p. e496). While genitals are definitely an important matter in sex-variance discourse, they are not the exclusive keystone of wellness for all individuals with sex-variances (although, to be sure, genitals damaged through cosmetic surgeries can serve as a catalyst for immense suffering and even suicide). Further, Lee et al. (2006) state that "it is generally felt that surgery that is performed for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and the parents; the systematic evidence for this belief is lacking" (p. e491), which effectively contradicts the paradigm of obligatory genital surgery. Rather than espousing the Chicago Consensus as a be-all and end-all approach, Lee et al. (2006) take a more modest position that admits to a dearth of knowledge and approaches regarding sex-variances.

Up to now, I have discussed literature that is informed by professionals, John Money having been a sexologist, and the authors of the Chicago Consensus being medical specialists. At this point, however, I shall turn to the Clinical Guidelines of the Intersex Society of North America (ISNA). Unlike literature designed for use only by professionals, the ISNA Clinical Guidelines are written with individuals with sex-variances and their families in mind as well, and are heavily informed by the voices of persons with sex-variances themselves. This insider-perspective allows the Guidelines to better represent the needs and desires of persons with sex-variances.

### **2.3 ISNA Clinical Guidelines**

In 2006, ISNA (<http://www.isna.org>), which has since merged with Accord Alliance (<http://www.accordalliance.org>), released a publication (ISNA, 2006) that provides a comprehensive undertaking of "patient-centred" (p. 1) clinical recommendations for practitioners who attend to individuals with sex-variances, engaging many issues that were discussed in the Chicago Consensus. Because ISNA is the organizational name used in the 2006 document, that is the name I shall use for the purpose of this thesis. The ISNA (2006) guidelines make a number of recommendations to professionals who serve individuals with sex-variances, and to the families of such individuals. They advise service providers to "provide medical and surgical care when dealing with a complication that represents a real and present threat to the patient's physical well-being" (pp. 2-3). They then recommend that those involved embrace diversity by not forcing service recipients to conform to normative values (pp. 2-3). Next ISNA (2006) advises "minimize the potential for the patient and family to feel ashamed, stigmatized, or overly obsessed with genital appearance [and] promote openness (the opposite of shame) and positive connection with others" (pp. 2-3). They then recommend that providers delay surgery and sex-hormone treatments until service recipients can take part in the decision-making process (pp. 2-3). I take this to mean that the patient in question is able to express an understanding of, and appreciation for, the realities of their sex-variance and any intervention(s) that may be applied thereof. ISNA (2006) next advises providers to "respect parents by addressing their concerns and distress empathetically, honestly, and directly" (pp. 2-3). They then recommend that those involved "directly address the child's psychosocial distress (if any) with the efforts of

psychosocial professionals and peer support" (pp. 2-3). Lastly, ISNA (2006) recommends that providers tell the truth to service-recipients and their families (pp. 2-3). These patient-centred recommendations lend themselves to the accountability and transparency of service providers, and to the empowerment, agency, self-determination and informed consent of service recipients, all of which are consistent with anti-oppressive social work practice.

ISNA (2006) discusses, at considerable length, the merits of a "multidisciplinary team approach" (pp. 9-19), an approach involving such specialties as child psychology/psychiatry, genetics and genetic counselling, nursing, social work, pediatric endocrinology, pediatric gynecology, pediatric urology, etc. (p. 11). This approach promotes an ethos of agency and autonomy on the part of service recipients, as well as empowering service providers with significant input in their own areas of specialization. Of particular importance here is that ISNA (2006) encourage providers to "spend their energies on developing local and networked systems that consistently provide patient-centered care rather than attempting to reproduce exactly what is outlined" (p. 9), meaning that the guidelines should be tailored to suit the needs of each service recipient and not imposed verbatim. What social work researchers may wish to do in this area is help to identify where gaps or limitations in professional service exist, and subsequently determine what service recipients would like to see done in terms of remedying these deficiencies.

ISNA (2006) discusses the matter of gender assignment of newborns with sex-variances, emphasising that such an assignment is "a social and legal process not requiring medical or surgical intervention" (p. 25). ISNA (2006) further indicates that

"gender identity development is the result of a complex interaction between genes and environment" (p. 25) and that "it is impossible to predict with complete confidence what gender any child will eventually come to identify with" (p. 25). Service providers are advised that "gender-atypical behavior is not a reason to encourage gender reassignment in the absence of the patient's desire for gender reassignment" (p. 26). ISNA (2006) includes here a discussion of why the presence of a Y chromosome does not automatically dictate a masculine gender development (p. 26), suggesting that sex and gender are far more complex than was thought in previous times. Regarding the matters of gender variation and of dissatisfaction with initial gender assignment in individuals with sex-variances, ISNA (2006) writes:

Gender assignment is an imperfect art; a small but significant number of patients with DSDs will develop a gender identity at odds with their initial gender assignment, and some will grow to feel and express nontraditional gender identities. It is best to let patients decide for themselves what anatomical features accord with their self identities. Professional counseling by a mental-health professional can help patients make these decisions (p. 28).

Ongoing research can help to keep service providers apprised of the most current evidence, both empirical and experiential, relating to gender identity and gender assignment in individuals with sex-variances. Such evidence needs to explicitly include inputs from individuals with sex-variances themselves. Equipped with an anti-oppressive approach to practice, social workers could help to direct research away from comparisons with sex-normative people, towards more robust understandings of people with sex-variances on their own terms. Further, instead of engaging only in short-term research, in

which service recipients/participants lose contact with service providers/researchers after a brief time, social work researchers may wish to engage in investigations designed to assess long-term outcomes. While such investigations may take years or even decades to conduct, they may serve to provide more comprehensive understandings in sites where there is a dearth of knowledge.

Lastly, ISNA (2006) offers wellness-related guidelines pertaining to six matters that are of importance for many individuals with sex-variances, each of which I shall address at this time. Firstly, the guidelines discuss peer support:

Peer support, both formal (in a clinical setting) and informal (through personal connections), often provides at little or no cost a critical form of care for patients and parents ... Peer support may also be provided through internet groups and through the offering of telephone numbers from family to family (p. 27).

Because social workers may be delegated to put service recipients and service providers in contact with resources, relevant research here may be used to connect social work practitioners with such things as sex-variance contact networks and peer support delivery strategies, which may be subsequently used to allow both recipients and providers to stay informed on a continual basis.

In a review of contemporary social support research, Hogan, Linden, & Najarian (2002) write:

Unfortunately, at this time, there is no consensus as to the most effective form of [social support] intervention or whether certain interventions are better suited to particular populations ... Matching patients to treatment may be especially

effective if it can be determined that certain patient subgroups are more likely to benefit from specific support interventions. (pp. 382, 431)

The door is open here to a large assortment of inquiries and recommendations pertaining to peer/social supports for individuals with sex-variances. Social workers may wish to engage such queries as exactly what functions sex-variance peer/social supports should provide, how contact with such supports can best be established and maintained, and what the ideal level of professional involvement with such supports is.

ISNA (2006) discusses "tackling shame":

When they leave the clinic, patients and families go out into the world and often encounter direct or indirect messages that they should be ashamed of themselves because the child has a DSD ... Meeting others who share similar challenges has been consistently identified by adults and families affected by DSDs as the single most powerful therapeutic experience. It is not uncommon to hear adults with DSDs and parents of children with DSDs say that connecting with a peer supporter saved them from a sense of growing desperation born out of a mounting shame (p. 27).

Here, social work research may be used to keep both service recipients and providers apprised of up-to-date understandings in the use anti-oppressive strategies to overcome the shame and isolation that individuals with sex-variances or their families may experience.

ISNA (2006) emphasizes the importance of telling the truth:

Telling patients the truth about their medical histories and conditions promotes a trusting doctor-patient relationship, signals openness (the opposite of shame),

reduces the sense of stigma, and enables patients to understand the health and quality-of-life benefits of adherence to medical care (p. 33).

Collaborative research here may bring about the emergence of progressive understandings of exactly what "quality-of-life benefits" entail, and those understandings can subsequently be shared with individuals with sex-variances, alongside candid disclosures of medical histories, so as to foster a more empowering environment in which the best wellness strategies are engaged by both providers and recipients alike.

ISNA (2006) elaborates upon sexual well-being, stating that "in the past, too much attention has been paid to genital appearance and gender identity at the expense of the patient's sexual health" (p. 34). In response to this, social workers engaged in research surrounding people with sex-variances may wish to ensure that genitals and gender identity are not overemphasised. Further, social workers may wish to help keep the sexual health discourse apprised of the sexual health needs of people with sex-variances, and of the various ways such needs can best be met.

Importantly, ISNA (2006) describes their approach to pharmacological interventions:

Endocrinologic therapy administered to avoid an imminent threat to the patient's health should be provided and explained to parents and, if of an appropriate age, to the child. The most obvious example would be treatments for classical CAH [Congenital Adrenal Hyperplasia – see ADAM, 2012] ... In general, elective sex hormone treatments can wait until the child is approaching the age of puberty when the patient can and should participate in informed decision-making. The administration of sex hormones can result in physiologic and behavioral changes

discordant with the developing self-identity of the patient. For this reason, it is best to have qualified mental health professionals assess the patient's identity and maturity and suggest options (pp. 30-31).

As sex hormone therapies are generally prescribed at an age when children tend to be old enough to more fully appreciate and understand the implications of taking them, the children in question should be involved in all treatment decisions to the extent that they are able. Ethical issues surrounding age of capacity concerns become central here, but a lengthy discussion of the exact nature of such issues is beyond the scope of this thesis. Needless to say, children should be properly assessed to determine if they truly understand and appreciate the risks and potential outcomes of sex hormone therapies before they decide to commence with them.

During consultations, children with sex-variances should be fully informed of the intended actions and potential side effects of any proposed sex hormone therapies, and should be asked if such treatments would concur with their identities. If a child is apprehensive, or is unsure of whether or not a suggested sex hormone therapy regime coincides with their identity, the social worker may relay this to the rest of the team, so that alternative arrangements can be advised. I note here that while sex hormone therapies are not intrusive in the same way as surgery, they can nonetheless cause pronounced and lasting changes that are both physical and psychological in nature. Erring on the side of caution here may help to avert a catastrophe.

The ISNA (2006) guidelines discuss genital surgery in the context of psychosocial wellness. While medical professionals are more apt to be able to inform parents of children with sex-variances about the risks and expected outcomes of such surgeries, the

guidelines speak of a number of areas where social workers may appropriately interject.

The guidelines indicate:

Genital cosmetic surgeries are sometimes offered to relieve parental distress, but parental distress should instead be addressed directly to peer support and competent mental health care ... Past practice favored the use of surgery to reinforce initial gender assignment. This included operations aimed at making genitalia look more cosmetically normal and the removal of gonadal tissue at odds with the initial gender assignment ... There is a consistent and growing body of evidence that children raised with "ambiguous" sex anatomy are at no greater risk for psychosocial problems than the general population. Meanwhile, there is surprisingly little published evidence to the contrary. As a consequence, there is a lack of demonstrated need for early cosmetic genital surgeries. Interventions have tended to be based on fears about "worst-case scenarios," not demonstration of medical need ... Allowing the patient to make decisions about elective care signals to the patient a fundamental valuing of his or her autonomy and personhood (p. 28).

In keeping with the principles of anti-oppressive social work practice, in valuing the rights and dignity of individuals with sex-variances, and in upholding social work ethics surrounding self-determination and informed consent, I ardently maintain here that cosmetic genital surgery should only be performed at the behest of, and with the explicit informed consent of, the individual who will have the surgery performed on them. I note that my ethical concerns here do not pertain to surgeries that are necessary in order to

address imminent threats to the physical health of a child, only the performing of surgeries that are cosmetic in nature.

On the matter of non-consensual cosmetic genital surgery, Butler (2004) writes: The argument is made that children born with irregular primary sexual characteristics are to be "corrected" in order to fit in, feel more comfortable, and achieve normality. Corrective surgery is sometimes performed with parental support and in the name of normalization, and the physical and psychic costs of the surgery have proven to be enormous for those who have been submitted, as it were, to the knife of the norm. The bodies produced through such a regulatory enforcement of gender are bodies in pain, bearing the marks of violence and suffering. Here the ideality of gendered morphology is quite literally incised in the flesh (p. 53).

Having explored and evaluated some of the central approaches within the modern literature surrounding sex-variances, I now move on to discussing the details of the study that is the focal point of this thesis. I will firstly elaborate upon the methodology used, then discuss inputs from study participants, and lastly provide an interpretation of these inputs. Afterwards, I will conclude this thesis with additional discussion, and with some closing remarks.

## Chapter 3: Methodology

### 3.1 Introduction

To reiterate, my goal in writing this thesis is to identify and explore some of the themes and issues that members of the social work profession may wish to consider when investigating matters or making recommendations that pertain to the wellness of individuals with sex variances. This chapter illustrates the research methodology used in this thesis, focusing on a number of topics: 1) the sampling framework; 2) the research design; 3) the data collection process; 4) the data analysis process; 5) ethical considerations; and 6) limitations of the study. In achieving the goal of this exploration, I utilized the qualitative method of Interpretative Phenomenological Analysis (IPA), a subset of phenomenology commonly used in the field of psychology (Larkin, Watts, & Clifton, 2006; Smith et al., 2009). Again, IPA focuses on people's lived experiences and how they understand them. Publicizing these experiences and understandings involves people telling their stories to researchers, who then interpret them. In this way, researchers using IPA take on a similar role to art gallery docents.

The IPA method is a valuable approach for exploratory research. It allows for the emergence of broad themes that reflect the voices of the participants. My own voice and experience in this research is present in the conversations with the research participants and in the data analysis. While it is indeed possible to describe what participants have said without interpreting and contextualizing the meanings therein, this is little more than parroting. IPA is advantageous in this regard, as it goes beyond being "simply descriptive", delving into deeper meanings (Larkin et al., 2006). IPA obliges researchers to use their own insights in shaping the final presentation that is put forth to the research

audience. In the case of this thesis, I possess first-hand knowledge of both what it is to be a person with a sex-variance and what it is to be a social worker. Through IPA, I am able to use my combined knowledge to present what participants have expressed in a way that more accurately represents their meanings, and which social workers can more readily understand.

There are two primary reasons for my choosing to use a qualitative approach in this thesis. Firstly, I am concerned with the qualities of wellness, how people with sex-variances understand wellness, and what influences these understandings. Here, qualitative inquiry is valuable in and of itself. Secondly, once the qualities of wellness are more thoroughly defined for any given population in any given circumstance, they can be woven together into a cohesive whole such that they lend themselves to a holistic approach. This approach can then be employed in designing strategies to facilitate the wellness of people with sex-variances. While the evaluations used may employ quantitative or hybrid approaches, they will be founded upon qualitative understandings. This is a site where qualitative inquiry is valuable as a conduit to quantitative results. For social workers engaging in evidence-based, anti-oppressive practice, we need both quantitative and qualitative understandings. The former allows us empirical understandings, while the latter affords us the empathetic understandings that we need in order to be able to relate to those we serve.

### **3.2 Sampling**

In recruiting participants, I used the purposive sampling approach of criterion-snowball sampling. I used the criterion approach because I wanted to acquire first-hand information about what wellness means to individuals with sex-variances.

Potential participants were required to be adults previously unknown to me who have a sex-variance. The individuals needed to be willing to partake in an in-person interview of approximately two hours, live in Canada or the contiguous United States of America, and be able to communicate in the English language. My rationale for using these criteria were several. To begin, only individuals with sex-variances themselves are able to provide firsthand accounts of what wellness means to them. This fact is self-evident. In terms of being open about having a sex-variance, this criteria was used to help ensure that any potential disclosure of participant identities would not also risk outing them publicly and causing harm to them as a result. The inherently vulnerable nature of children, coupled with the vulnerable nature of being an individual with a sex-variance, made interviews with children with sex-variances prohibitive in terms of acquiring ethics approval. By only recruiting adults as participants, I was able to evade this issue. By making participants aware of the interview length ahead of time, I was able to recruit participants who were able to make this time commitment. Further, travel abroad was cost-prohibitive, such that I chose to restrict my participant recruitment to geographical areas that I could readily access. I only speak English, and the ability to communicate in person directly with the participants was a central aspect of establishing the rapport necessary for in depth interviews. Ethical/confidentiality requirements prevented me from conducting the interviews with a translator present. Finally, by only interviewing participants who had not been previously known to me, I was able to help ensure that I did not have any preconceived notions about participants and that I was able to avoid any conflicts of interest due to a dual-role relationship.

I used the snowball approach because it seemed to be the most effective approach to recruit research participants. Individuals with sex-variances are difficult to reach, in part due to their representing a very small portion of the population, and also in part due to issues of distrust for health professionals (potentially including social workers) resultant from deception, concealment, and non-consensual interventions. A further benefit of the snowball approach is that it streamlined the recruitment process by having me referred only to individuals meeting the recruitment criteria.

Rather than relying on existing participants for referrals to other potential participants, I used contact persons associated with online sites for people with sex-variances. These sites included email lists, websites, online forums, and online social media venues. I also used contact persons associated with in-person organizations for people with sex-variances. These included support groups, advocacy groups and community centers. Contact persons were emailed a recruitment form (Appendix 1) and were asked to instruct interested persons to email me directly. When potential participants contacted me, they were not asked how they came to learn of the research project. While this helped to ensure the maintaining of confidentiality, it prevented me from keeping accurate recruitment statistics. Although some participants informed me of how they came to learn of the research project when I met with them, I kept no records of this.

In the end, four participants successfully completed the interview process, three of whom identified themselves as men, and one identified herself as a woman. Each participant indicated the name of the sex-variance condition that they were diagnosed with. As the names of people, places and sex-variance conditions could be used to

personally identify participants, these were redacted from the final write-up. Participant names were replaced with pseudonyms so as to avoid confusion in the final report. Ascertaining that each participant did indeed have an identified sex-variance was important in terms of study integrity. Because this research relates to sex-variance wellness in general, rather than in terms of any specific conditions, study results were not compromised by redacting the names of participants' sex-variances.

### **3.3 Research Design**

The formal process of research involved three primary stages: data collection, data codification, and interpretative analysis. Data collection firstly involved recruiting participants, then scheduling interviews with participants, then partaking in the interviews themselves. As mentioned above, the participant recruitment process involved a criterion-snowball approach facilitated by gatekeepers associated with sex-variance organizations. While the interview scheduling process involved some degree of negotiation, it was fairly straightforward. The most engaging component of the data collection process was the actual interviews. During the interviews, I prompted participants to speak about a variety of topics, but did not have any prearranged interview schedule. This allowed participants a great degree of control over the interview process, which served to both empower and build rapport.

Data codification involved repeatedly sifting through the transcribed interviews until cohesive themes emerged. These themes were then compared with those in the rest of the interviews and given a label indicative of their general subject matter. Lastly, in terms of interpretative analysis, I interpreted what participants said in relation to each of the broad themes. I did this in a manner intended to be readily comprehensible to social

workers. This was the most challenging component, because it involved a great deal of introspection in bridging the gap between sex-variance and social work. I had no clinical manual or guidebook for this process, relying instead on my own lived experience and understanding. To be sure, this interpretative process was by no means scientific, but was largely intuitive. However, given that this project is situated at the initial, exploratory stage of social work research surrounding sex-variance wellness, the need for rigid empirical structure did not present itself.

### **3.4 Data Collection**

Interviews were semi-structured and approximately two hours each in length. I followed the interview guide in a loose manner that allowed participants to negotiate the interview process as they saw fit. Rather than using a regimented approach to the subject headings in the interview guide, I gave participants subtle prompts designed to encourage conversation surrounding each subject heading. Generally speaking, this involved the use of segue questions to introduce each new subject and to get participants talking. I found that the participants were eager to talk, and did not require much prompting. In order to maintain a greater degree of connection with participants, I recorded the interviews with a digital voice recorder. I omitted the taking of handwritten notes during the interviews, performing this task immediately after each interview concluded.

The semi-structured interview format was used for a number of reasons. Firstly, it allowed me sufficient control over the subject matter discussed during the interviews, and allowed me to ensure that the interviews remained in accordance with the research objective. Secondly, although there was a predetermined schedule of questions, the semi-

structured format empowered participants to shape their answers to these questions in any way they saw fit. FAO (n.d.), in discussing the advantages to using semi-structured interviews, indicates that they are "less intrusive to those being interviewed as the semi-structured interview encourages two-way communication" and also that "when individuals are interviewed they may more easily discuss sensitive issues." The semi-structured interview provided a mixture of structure and rapport, allowing participants to tell their stories while allowing me to conduct an in-depth interview around matters pertaining to wellness. I based the interview guide (Appendix 3) around social institutions that I expected participants to be involved with throughout the course of their lives. The education system, parent/family, social networking, the community at large, romantic/intimate relationships, and the workplace are all social institutions that an average person could be expected to have experience with. I asked about the child protection system and the legal system out of force of habit. These are matters that social workers typically ask service recipients about. The protection of rights and interests is a matter that all persons, especially vulnerable persons such as individuals with sex-variances, are routinely concerned about. The health system, and identity formation in terms of sex, gender and sexuality, are areas that individuals with sex-variances are apt to have ample experience with. This was indeed the case. In order to help ensure that the interviews were as comprehensive as necessary, I expressly asked participants if there were any other areas that I missed asking about and that they would like to talk about.

### **3.5 Data Coding and Interpretative Analysis**

Interviews were transcribed, and then emergent themes were distilled using the following stages: to begin, I coded each statement made during the interviews into a brief

synopsis containing of the gist of what the participant was saying. Next, I extracted themes from the synopses, assigning a one or two word heading to each. After that, I grouped the headings into thematic categories (for example, "websites", "sex-variance organizations" and "mentoring" were all assigned to the thematic category "resources"), which allowed me to compartmentalize the data for analysis. These first three stages involved a synthesis of data coding techniques used in grounded theory (Glaser & Strauss, 1999; Bryant & Charmaz, 2010), IPA (Smith, et al., 2009), and other qualitative methods (Wertz, Charmaz, McMullen, Josselson, Anderson, & McSpadden, 2011).

My decision to use IPA was based on it utilizing thematic emergence (Smith et al., 2009). By not having a rigid interview schedule, but instead allowing participants to have control over the interview flow, I wound up with a bulk of unsorted data. In sifting through the interview transcripts again and again, the major topics of discussion, or themes, appeared. From here, I was able to identify and label these themes. Having previously distilled both themes and theory in prior research, I was confident in my ability to use similar techniques in this thesis.

I did not use any data management software for this research project, but instead used both numbered and color-coded tags in performing the thematic distillation. My decision not to use data management software was based on budgetary constraints and on the small number of research participants. The small number of participants and the relatively small number of topics addressed in the interviews allowed me to make efficient use of the labelling capabilities found in my existing word processing software.

### **3.6 Ethics**

Ethics approval for this study was sought through the Dalhousie University Social Science and Humanities Research Ethics board, which granted approval for the study in December 2011. This ethics approval concludes in December 2014. Upon meeting each participant for their interview, I handed them the consent form (Appendix 2) and allowed them time to either read it or listen to me read it. After reading the form, I asked the participant if anything on it needed clarification. After making clarifications (where necessary), I asked each participant if they understood the contents of the form, and asked them to sign the form if they said that they understood. Lastly, I signed the consent form myself.

Confidentiality was a primary ethical consideration throughout this research project. Maintaining confidentiality reduced the risk of information personally associated with participants' identities from being revealed publicly. This helped to ensure that the shame and stigma that often accompanies sex-variances was not perpetuated by this research. Further, maintaining confidentiality helped to establish trust and rapport between participants qua individuals with sex-variances and me qua a social work professional. There is a history of health professionals violating the trust of individuals with sex-variances through the use of such practices as non-consensual interventions, maintaining secrecy and withholding information. As such, any violation of confidence on my part could serve to amplify this skepticism.

### **3.7 Limitations**

The findings presented in this study are not conclusive or transferable. Further, given the small sample size, coupled with the fact that each participant reported having a

different sex-variance condition, there is no way that this thesis yielded findings that are representative of any person other than the participant in question. However, I did not partake in the study in order to make exacting claims. My intention was to perform some incipient research from which I could relay ideas to social workers who want to move forward with sex-variance wellness research. In this respect, the research here was less complex and less in-depth than subsequent research may wind up being.

As already mentioned, this study was not generalizable. Although the small sample size was adequate for an exploratory study using the IPA method, the scope and size of the study was insufficient to establish generalizability or transferability of findings onto persons with sex-variances in general. Further, this study was a broad-based inquiry into the matter of sex-variance wellness, and was not about any particular sex-variance conditions. The needs and desires associated with any given sex-variance condition could well be expected to differ in comparison with another. With its exploratory nature, this study was not designed to compare or contrast needs and desires across the populations with various sex-variances. The purpose of this study was to introduce a few themes that pertain to sex-variance wellness, and to do so in a way that is readily comprehensible to members of the social work profession.

In recruiting participants, I relied upon contact persons associated with sex-variance organizations for assistance. Here, there was room for bias that would not have been present in a random sample. Contact persons had the capacity to direct me to some prospective participants, while not directing me to others. This may have given contact persons the opportunity to engage in censoring for reasons unbeknownst to me.

### **3.8 Summary**

In this chapter, I have discussed the sampling strategy I used, namely the purposive sampling approach of criterion-snowball sampling. I detailed the research design components used in this thesis, which involved data collection, data codification, and interpretative analysis. Under the data collection heading, I discussed the semi-structured interview format that I used, as well as the social institutions that were explored in the interviews. Under the data coding and interpretative analysis headings, I discussed the synthesized approach that I used to achieve thematic emergence. This involved my own modality adapted from a number of qualitative traditions. Further, under this heading I discussed the IPA approach that was used in interpreting what participants said during the interviews. Lastly, I provided an overview of the ethical considerations involved in the study, as well as and the study limitations.

## **Chapter 4: Findings**

I have removed the names of all people, organizations and geographical locations mentioned during the interviews or the recruitment process, and have further removed the names of the medical conditions that the participants disclosed having been diagnosed with. I did this to ensure confidentiality of the participants. As this study is focused on outcomes for individuals with sex-variances in general, rather than on outcomes for individuals with particular sex-variance conditions, I do not expect the removal of condition names to have a considerable impact on the findings or recommendations that follow. In order to better humanize the research participants' accounts while still maintaining confidentiality, I have assigned a pseudonym to each participant – Carl, Dina, Max, and Nick, respectively.

### **4.1 Medicalization**

Medicalization was a prevalent theme in this study. I use the term medicalization to mean those sites where medicine takes on the roles of defining, describing and understanding matters surrounding wellness, promoting wellness, and treating barriers to wellness (Conrad, 1992). I use the term overmedicalization to mean those sites where medicine takes on roles above and beyond the promotion of wellness and treatment of barriers to wellness, such that it becomes an agent of social control. I shall discuss medicalization in greater detail in chapter 5.1.

A portion of each interview involved discussion surrounding a lack of knowledge or skill on the part of the physicians involved with the participants. Dina voiced open disdain for the way her doctors approached her and her sex-variance:

I would say that I have developed a dislike and distrust of the medical profession. I think they did sloppy work a lot of times. They did a sloppy job of helping my parents decide whether I should be a boy or a girl. They could've been better organized when I was a baby, so that all of the information needed to make a decision about what sex I'd grow up as could've become all available all at once, early on.

Dina further discussed having a bilateral mastectomy imposed upon her as a youth: "I started developing breasts, and the doctors told me that this just happens sometimes, and that they have to be removed." She then criticized having been provided with counselling in place of the candid, straightforward provision of information. She said that "counsellors help people figure out their own feelings and thoughts. But in my situation, I didn't need to work through my own feelings, I needed information."

Carl discussed having a series of genital reconstructive surgeries as a child, which proved to be largely in vain, as it was necessary to repeat the procedures even into his adulthood. He stated "I was in the hospital frequently [as a child] ... I thought it was a rite of passage almost, except that I noticed my [siblings] never had to go through this rite". He elaborated by saying "In my youth, my parents were told to never discuss anything [about sex-variance] and they didn't". He discussed being informed by a urologist as an adult that he had received numerous genital surgeries as a child. Carl also voiced dissatisfaction at having to return for surgical revisions over and over again, even though the surgeons did not discuss the possibility that the surgeries may fail. Of one of his surgeons, he said "so I go in for surgery, and the next day everything is oozing. Seven

surgeries later in six months he said that there was nothing else he could do, that there was no one he could refer me to."

Nick told me about how his doctors were overbearing to the point of being difficult to approach or communicate with. He made such statements as:

When you meet a doctor and they are in a lab coat, they seem like they have this air of authority and sometimes you worry what kind of reaction you're going to get from some of your questions, and sometimes you're too embarrassed to ask them because for some reason, with all of the accoutrements, they seem less than easy to talk to. I don't know if it was the feeling of being judged or the fear of maybe asking a stupid question or what, but I always felt trepidation when it came to asking about the different treatments options that I may go through."

For all participants, medicalization was a source of frustration, which I shall discuss forthwith.

## **4.2 Frustration**

Each participant expressed a degree of frustration surrounding the treatment they had received as individuals with sex-variances, much of which was directed at the deceitfulness and conceitedness of the medical and health professionals – particularly physicians – they have received services from. Carl stated that "when I go to the hospital, the doctors rights are protected and not mine. If I see a therapist, I have to train them."

Further, in discussing one of the surgeons he saw for a procedure, Carl said:

The problem that occurred from this surgery was he [the surgeon] simply wanted to fix the stricture, he wasn't concerned about appearance or function... He wasn't worried about erections, he wasn't worried about appearance. And that's my fault

for not nailing him on that to begin with. But it's experience, you know when you come from people where that's the norm, then I expected that to be the norm throughout.

Carl discussed his parent's secrecy surrounding his sex-variance:

If they would've told me to begin with [about my sex-variance], I wouldn't have felt like a freak when I hit puberty. Okay, information was withheld, but my father would periodically examine me and not explain why. He would just say "you're going to have trouble getting a girlfriend", really horrible things to say to a child. I didn't understand, I had lots of girlfriends. So it was non-sexual, yes, because I grew up to be gay.

Carl also discussed confronting his parents about them hiding the truth of his sex-variance from him:

I wrote this 20 page letter to my parents and I said "you never told me". Every emotion in the world went into in this letter. My mother wrote back and said she still had copies of all of the original records. She had had me tested to see if I was a boy or a girl. She said that the doctor was right, that I had had seven surgeries as a child. [John Money] said to "never give an inkling [about the sex-variance], and if he starts to talk about it, to change the subject." I got mixed messages the entire time I was growing up. Until it all came out into the open.

Dina voiced discontent at the misleading and disorganized information flow that her parents received from her physicians:

The doctors told my parents when I was a newborn that all they had to do was have me see a plastic surgeon and that the plastic surgeon would fix me up and

that I would be like other boys, and that would solve the problem. And when I had a consultation with a plastic surgeon at about 1½ years old, the plastic surgeon said that there was not enough phallic material and that this child can't be reconstructed as a boy. I don't think the doctors actually were explicit to my parents about that. I think they were probably a little bit evasive, they didn't want to say that they'd made a big mistake and that they won't be able to do this operation.

Dina further discussed how these medical indiscretions occurred even as she was a teenager (and thus much more able to appreciate the realities of her situation than when she was a young child):

At the time when I was developing breasts, my father told the doctor that he should tell me everything that he knew [about my sex-variance], and should tell me of the possibility of changing to live as a girl. The doctor wrote in his notes that my father was pressuring me to change to live as a girl, which was not happening. The doctor attributed my being very upset at his office to that, which was not true. And the doctor did not comply with my father's instructions to give me this information. In fact, years later, my father said "didn't he tell you all this stuff? I asked them to tell you, didn't he do it?" From the doctor's point of view I didn't need that information.

Nick, presented as very reserved and somewhat docile during the interview.

However, in telling me his story of a lifetime of medicalization, he mentioned trying to escape during one particular set of medical examinations:

I hid under the bed and I was hanging to the boards under the hospital bed trying to hide, and they tried to get me out from under there. A very large individual, pulled me out from under the bed. I was so embarrassed that I ran and hid in the laundry basket in the hall, and they couldn't find me for a while.

Nick's actions here illustrate the high level of angst and difficulty that he was experiencing as a medicalized child. He was clearly unhappy about the way he had been treated.

During my interview with Max, he was vocal about his disdain for many physicians, depicting them as egotistical and outmoded:

We didn't come very far away from the leeches a couple hundred years ago. If we're expecting the medical community to all of a sudden turn around and turn its back and say "oh yeah we get it, so we're going to be doing it this way and this way", it's not going to happen. I find them kind of stoic, they do somewhat move, but they'll move for movers and shakers that make them actually want to move.

Otherwise, they like to stay in the same spot they always are, and that is as the god figure. Now, as the god figure, you know everything and nobody can tell you anything else. So at this point, you become a dinosaur. We're not looking for dinosaurs anymore, we're looking for people who are innovators.

#### **4.3 Shame and stigma**

Three participants discussed shame and stigma in relation to sex-variances. Carl indicated that:

Sometimes a lot of us are so isolated that when we are around others we look at their perception ... I've also seen some diagnosable mental issues in a lot of

intersex people. I don't want to say what percentage or anything like that, but I've met several, either bipolar, or there were many schizophrenics. A lot of alcohol and drugs, a lot of anxiety. I wish there was a way to let them all know that there are people that care, because a lot of them feel so isolated.

Nick said:

In junior high and high school, all of my other friends had gone through puberty already. They were already falling in love, and I didn't feel any of that. And I would actually have people ask me on dates and things like that, and I had to turn them down because I knew that I wasn't at the same place that they were, and that was rough.

Max discussed having to blend in, in order to avoid being stigmatized:

The last thing you want to do as a child growing up is to have labels, where you are aside from the crowd, [because] you are more likely to be bullied and more likely to be left alone, and being a social person you don't want to be left alone. So you blend in, in order for you not to have that pain and anxiety and stress, being alone in a society that shuns you for the person you are. So you learn to blend. You learn to become a chameleon in your life, where you can be one person in front of them, but you know full and well you're not that person.

#### **4.4 Public washrooms.**

Dina and Carl both discussed using public washrooms, illustrating how this can be a daunting ordeal for some persons with sex-variances, while not for others. Dina indicated:

The main problem I had with the education system was using the bathroom at school. Because the system was for at a scheduled time of day the whole class, all the boys in the class to be brought to the boys room and use the boys room at the same time and I had so much teasing on those occasions that I just stopped using the bathrooms at school. Throughout my entire life until I changed to living as a girl, I was very uneasy about using public bathrooms.

Carl, on the other hand, said:

There were no problems, because if there was no erection, you could not tell.

Some of my contemporaries used the teacher's facilities and things like that, but I didn't find that necessary. It was okay to be in public. I knew I could pass.

#### **4.5 Self-identity**

The participants all discussed their self-identities, with each revealing a unique set of experiences.

Carl stated:

I'm tired of being in the closet about my own life. It was one thing being a gay man, and I never felt like one of those either. If I had to put myself in a category, it would totally be intersexed.

More light is shed on Carl's identifying as *intersexed* in his stating "What am I? There have been times in my life where it appeared that I had both a vagina and a penis."

Dina stated:

When I was [a young adult], completely on my own, I found out all about [my condition] and I realized that I should have been a girl ... over the next few years I was going through sort of a crisis in my life. I was sexually attracted to males

and I did not see any way that I could have a sex life living as a boy and I also thought it would be impossible to live as a girl ... then I found out that there was such a thing as breast reconstruction and that was the pivotal piece of information for me.

Dina further indicated having had a bilateral mastectomy as a teenager, despite a plastic surgeon having informed her parents during her childhood that "this child should have grown up as a girl, because there is not enough phallic material to make into a functional penis".

Max said:

I feel that my intersexuality puts blinders on things [to do with gender] that most people find pertinent. I know a lot of people who put a lot of value into how a woman or a man thinks, but I put no value into that whatsoever"

Max further indicated that he felt a great deal of confusion over this gender-ambivalence/apathy until he was informed as a young adult of his having a sex-variance condition, stating "[my doctor] let me know that there is a medical reason for why I feel both sides." Nick spoke of identifying as "asexual and celibate", until he started testosterone injections as a young adult, at which time he immediately began to identify as gay. He additionally expressed a sense of gender-ambivalence/apathy, stating in that regard that "I wasn't like any of the other guys that I had met".

#### **4.6 Intimate partner(s)**

Three participants indicated having been involved in intimate relationships, and spoke of having done so either in a predominantly or exclusively long-term capacity.

Max spoke of discovering that he was incapable of having his own children, and the impact that might have on his intimate relationships:

I guess that affected me to a certain extent. The option of adopting a child would have been relevant at that point, so I saw that more as a conflict with my future spouse than I saw as a problem. Some people really put a lot of value into having their own children, or else they're not a man or they are not part of the family and so forth. Well, I didn't have that. It was more relevant for me that if I found myself a wife, that she would understand."

Carl discussed how getting over the fear of being rejected on account of his atypical genitalia was greatly beneficial to him:

I knew something was different [about my body]. I knew that was different, but I never had problems. There were always people that went "what happened to you?" And I would lie and say "well, I was in a car wreck and the steering wheel hit me there", because I had no answer for what it was. But then once I discovered that people can love you for who you are, it made all the difference in the world.

Dina discussed how she stayed away from intimate relationships on account of her having been wrongfully raised as a boy:

I completely avoided romantic relationships while I was living as a boy. That was part of the reason why that became intolerable, because I felt that I was shut off from romantic relationships. I started dating within a few months after I transitioned ... I've never had casual sex and I have always been a somewhat shy and retiring person, and that's probably the result of my being intersex. I've only had what you might call serious relationships.

Nick, who had never been in an intimate relationship, stated that "for me, friendship is like the pinnacle of all my relationships. I didn't feel comfortable with other people going beyond that." Nick's statement speaks to how platonic relationships alone may sometimes provide sufficient emotional fulfillment to those persons for whom sexual intimacy is either not desirable or not feasible.

#### **4.7 Family**

All of the participants described very different family lives. Three participants spoke of deception by their families surrounding their sex-variances, ranging in magnitude from a lack of candidness to outright concealment. They attributed this to factors such as inadequate information given to their families by medical professionals, conservative views by family members, and feelings of shame. Carl said:

I think if my parents would have told me, then I would have had a better sense of self. I think I would have gone "I'm just different". I had no problem with that. I would have been okay being different.

Dina informed me that her "father did not get really full information from doctors, so he was under-informed."

Although none of the participants revealed any hatred towards their families for being less than honest about their sex-variances, there was a common undertone of wishing that things had been different, of wishing that they had received full disclosure at a younger age. Nick and Dina mentioned having family members with sex-variances, with Dina indicating that her cousin with a sex-variance committed suicide, and that the situation served as "a wakeup call" for her. Nick discussed a hesitant admission from his parents surrounding his sex-variance when he was an adult, stating that "my mother

finally explained to me that I had [atypical gonadal development]". Other than this, Nick had very little to say about his relationship with his family. Max quickly diverted the topic when I asked him about his family, and I asked him no more about the matter during the interview.

#### **4.8 Peers**

Each participant reported a unique account of their experience with peers. Nick spoke of being generally well-liked as a child, but having experienced alienation and isolation as an adolescent:

Going through my own unique medical history, when everyone else was going through things like the throes of puberty and whatnot, a lot of people would quietly back away from me because they knew that they were becoming an adult and that I hadn't gone through puberty yet, and they kind of realized if they hang around with me, that they would seem younger than they are. I noticed a friendship flight in my grade school years. I noticed that the older I got, the more alone I was.

Nick also discussed his sexuality in terms of coming out as gay during high school, indicating that this exacerbated the alienation and isolation he was feeling, but that he was eventually able to resolve it with the help of a relative who "had gay friends that she introduced me to, and this really helped to break the ice [with the gay community]." Dina gave her account of peer interactions, revealing some stigmatization surrounding her sex-variance:

The children at the school I went to believed that I had something wrong with me sexually and I was strongly stigmatized for that reason. I tended to not socialize

with children that I went to school with. I had a different social group from a different part of town. I got along better with [them] because they didn't know me at school. They didn't realize I was different in the sex organs, so I wasn't stigmatized.

Max spoke of having difficulties interacting with male peers, but indicated that he was eventually able to resolve this through finding accepting peers:

I did not get along with most males. I still don't. Being the person I am, I couldn't hide, so I was bullied a lot. Later on, I found people who were accepting of me for who I was, and that was okay from there.

#### **4.9 Sex-variance community and capacity-building therein**

Three participants spoke of a sex-variance community. Dina was the most skeptical of the participants, citing factionalism and infighting as substantial barriers to a genuine sense of community:

The intersex community came about with the Internet. In a sense it exists. Just imagine a road and there are houses on the side of the road and people live in proximity to each other and it's incorporated as a municipality, but people don't talk to each other a lot. Well, yeah, you could say that's a community. People communicate a little bit, but it isn't as though they are an intimate family where everyone is interacting and everyone feels responsible for everyone else. The intersex community is very fragmented, it's divided into a lot of small groups.

Carl spoke about a more tightly knit sex-variance community than Dina, stating "I definitely have a sense of community." He also discussed sex-variance community advocacy that involves the use of professionals:

[One of the attorneys] has brought us all together; she wanted people who were from the various organizations to sit with all of the attorneys so they could have a grasp of what we were doing, so that they could advocate for children and their parents.

Nick briefly spoke of inter-organizational conflict within the sex-variance sphere, saying "I realize there are lots of other groups out there that don't agree with my group. I hope that at some point in the future there will be a greater understanding about a lot of these [sex-variance] issues."

## **Chapter 5: Data Analyses**

In this chapter, I will interpret the themes which emerged from what participants said during the interviews. Afterwards, I will make recommendations aimed at social workers who attend to the rights, needs and desires of individuals with sex-variances. I will endeavour to avoid being overly forceful with my expansion of participant statements into the larger context, however, as this study is too exploratory and with too small of a participant base to be generalizable. As the generalizability of findings was not an intended outcome for this study, I do not feel that the lack of it is in any way detrimental.

Earlier, I made an analogy to art gallery docents, indicating that their work is akin to researchers using IPA. At this time, I would also like to add that any given docent will give a completely different art gallery tour compared to a tour by another docent. One docent might claim, for example, that Leonardo da Vinci was a mastermind. Another docent might claim da Vinci was imprudent. Neither of these positions is correct or incorrect in an empirical sense. They are simply interpretations. Further, it is not necessary for interpretations to be contradictory. It may well be the case that da Vinci was an impudent mastermind. In the case of interpreting participant inputs from this study, it may well be the case that another IPA researcher would draw somewhat different interpretations than I did.

### **5.1 Medicalization**

Conrad (1992) indicates that "medicalization consists of defining the problem in medical terms, using medical language to describe the problem, adopting a medical framework to understand a problem, or using a medical intervention to 'treat' it" (p. 211).

However, he also points out an ambiguity in defining medicalization, saying "the term has become used more often in the context of a critique of medicalization (or overmedicalization) than as a neutral term simply describing that something has become medical" (p. 210). For the purpose of this thesis, I use the term medicalization to mean an appropriate use of professional intervention, and the term overmedicalization in the problematic sense. This is not to suggest there is a clear-cut distinction between medicalization and overmedicalization. On the contrary, I use medicalization–overmedicalization as a continuum.

Sex-variance conditions may involve metabolic effects that may pose an imminent threat to health, and thus require intervention. This is an example of an appropriate site for medicalization. Sex-variance conditions may produce atypical genitalia, which become subject to the purview of medicine not because they create imminent threats to wellness, but because they violate normative ideology. This is an example of overmedicalization. To further exemplify, having sex-variances may result in stigmatization, which, while impairing wellness, may not need professional intervention. Some people may find ways to overcome stigmatization on their own and become more resilient as a consequence, while others may experience profuse psychological trauma as a result of being stigmatized. At what point should the health and medical professions intercede? The answer to this will no doubt be extremely complicated.

The issue for participants was not that health and medical professionals acted, but the way in which they acted. When these professionals acted to facilitate wellness, participants were not at all bothered by it. However, when these professionals acted within the context of overmedicalization, participants were distressed. Participants were

especially unhappy when professionals acted as agents of social control, engaging not only in overmedicalization, but in creating a definitive barrier to wellness. Here, participants were not treated as people in need of care, but as a means to an end.

The study showed that participants were harmed by unnecessary surgical modification or ablation of their genitals and breasts, and that this created a great deal of pain and suffering for them. Carl felt mutilated, and had never fully recovered from his numerous surgeries. Dina suffered until she discovered that her surgery could be reversed to some extent through breast reconstruction. Nick felt that health and medical professionals had domineered him and taken his voice away. Here, the health and medical professionals involved were not champions of wellness, but agents of social control. Ideally, social workers operating so as to benefit wellness could have been involved in these situations. Here, they would have been able to explain to service recipients or their families how others who had undergone the recommended procedures were impacted, and helped recipients/families make properly informed decisions based on this. Social workers could have also acted as advocates for service recipients, equalizing the power between them and the professionals whose care they were under. Social workers could have prevented a great deal of suffering, working towards social emancipation and against social control.

Based on the findings of this study, health and medical professionals should be forthright and transparent when addressing sex-variance issues. Professionals should carefully explain to service recipients or their families the realities of the situation, the available treatment options and alternatives, the potential risks of each option, and the prognosis if nothing at all is done. Treatment should only be recommended where it can

be expected to yield a bona fide wellness benefit to those receiving it. Social work can play a vital role here, helping service recipients and their families see through fear and panic to making the most beneficial decisions possible, and providing advocacy that can help to abate discrepancies in power.

## **5.2 Frustration**

Frustration describes the angst and despair that participants felt towards their health and medical providers. Frustration developed later on in participants' lives, as they began to appreciate the full effects of the harms done to them by their health and medical care providers. This frustration was primarily a result of the deception and secrecy that these professionals employed surrounding participants' sex-variances. The frustration was further compounded by the inability of these professionals to provide positive impacts through the interventions that were imposed upon participants. Participants did not express frustration at the inability of professionals to act, so much as at professionals doing the wrong thing. Participants were especially frustrated by their needs being minimized in the face of professional authority. This was especially the case in relation to medical doctors, but other professionals, including counselors, were also mentioned by participants as being a source of frustration. An air of superiority on the part of professionals certainly acted to daunt participants, adding to their frustration. Although participants did not talk about power inequalities by name, discussion of this matter was found in the subtexts and nuances of their statements. Participants wanted their rights and needs to take priority over professionals' credence and authority, yet it is exactly the reverse that transpired. A further source of frustration was the perpetuation of secrecy and deception by participants' families. Although participants were upset with their families

in this regard, the frustration they felt was directed at the medical professionals who told participants' families to employ secrecy and deception surrounding their sex-variances. Some participants were able to rekindle their relationships with their families, while others were not.

One way that professionals can better assess what the needs and desires of their service recipients are, is to communicate with recipients on a more level playing field. Here, in working with individuals with sex variances, social workers can play a key role by acting to diffuse power inequalities between service providers and recipients. This can be achieved through providing recipients with the necessary advocacy to make their voices both heard and heeded. Further, social workers are ideally suited to encourage forthrightness and transparency from other health and medical professionals. This would help to make sure that service recipients or their families are made aware of all of their options, both typical and atypical, so that they can pick which ones they think are going to work for the best. No one is going to be harmed if all of the cards are laid out on the table, even if some of the options put people off. Conversely, withholding information is inherently harmful. While health and medical professionals' training allows them certain insights that are unavailable to those without such training, this does not mean that they necessarily know what is best in any given situation. An individual knows themselves better than anybody else. In the case of young children, no one knows them better than their own family. In Dina's case, if the doctor had heeded her father's advice to tell her of her option to change living as a girl, this would have prevented years of pain and frustration. This would have prevented Dina from needing to have surgically reversed the effects of earlier surgery. As social workers, we pride ourselves in being able to

champion the rights and well-being of those we serve. Since recipients' rights and well-beings are central to our profession, we can take it upon ourselves to ensure that they are upheld by all of the involved service providers.

Although Max did not feel like he was being subjected to undue influence, he most certainly felt a great deal of frustration having his particular symptoms addressed while his whole self was ignored. Social workers could have resolved such a problem by introducing a holistic biopsychosocial approach. It's not as if this approach is specific to social work, and that other health and medical professionals are incapable of employing it. It is likely the case that these professionals get so caught up in the fine details of their specializations that they and simply don't see the forest for the trees. As this is a foundational approach in social work, we can prompt other health medical professionals to pay attention to it as well.

### **5.3 Shame and stigma**

For the participants in this study, shame and stigma represented the constant reminder that they were not only different from other people on account of their sex-variances, but less worthy as well. Participants seemed resilient for the most part, able to overcome a portion of the societal condemnation they faced. However, some of the shame and stigma became internalized, interfering with participants' sense of self-worth. In discussing high rates of addictions, mental health problems, and suicidality among individuals with sex-variances, Carl highlighted the hopelessness and despair that shame and stigma can bring.

During the interviews, Carl discussed “passing” and Max discussed blending in, both of which were strategies that these participants used in attempting to defeat shame

and stigma. What these participants did was figure out how to avoid alerting others to the fact of their sex-variances, and in doing so, gave others no reason to impose shame and stigma upon them. While this strategy was certainly beneficial, social workers working with people with sex-variances need to be aware of the fact that the process of blending in and passing may be internalized, such that the affected individuals may begin to feel that their situation is worthy of the shame and stigma, and that they need to hide it because it is somehow disgraceful. This is a double-edged sword that social workers need to know how to navigate. Shame and stigma on one hand, and passing and blending in on the other, are not only part of the lives of people with sex-variances, they are also part of the lives of members of LGBT communities. These are communities with which the social work profession is already very familiar and involved.

This offers a segue into another intervention strategy: confronting shame and stigma through visibility and openness. While it may be useful to be adept at blending in or passing, it would be much better if this were completely unnecessary to begin with. Given that the proportion of the population who are not heterosexual is substantially larger than the proportion of the population who have sex-variances, the same "out and proud" strategies used by the former may simply not be available to the latter on account of sheer numbers. This is where allies can save the day. Social workers can help here by engaging in sex-variance outreach with LGBT communities and the larger community. In this case, there most certainly is power in numbers. The more that people oppose shame and stigma surrounding sex-variances, the faster there can be a societal critical mass in which people with sex-variances become more welcomed by the larger community. As community and capacity development are core specializations within the social work

profession, social workers are already well-equipped to muster opposition against shame and stigma through outreach. Further, if people with sex-variances are able to experience a more welcoming world, then their internalization of shame and stigma can be abated as well. Common sense dictates that people are less prone to feel ashamed of their differences when those differences are seen as being welcome by the larger community.

#### **5.4 Public washrooms.**

In using public washrooms, Carl expressed confidence in his ability to pass. Underneath this confidence, however, was the ever-present awareness of the need to pass in the first place. Failure to pass could have serious and even menacing consequences. These consequences impacted Dina, who avoided using public washrooms for a fair portion of her youth. This part of Dina's story was evidence of just how pervasive and overriding heteronormative ideology can be. Even a mundane activity such as using the washroom is subject to heteronormative surveillance — to the heteronormative gaze. Dina and Carl are not outliers. Their fear, frustration, and shame and stigma surrounding public washroom usage are echoed by countless people in communities across each of the three pillars of sex, gender and sexuality, and beyond. The inability to use public washrooms safely most certainly has repercussions. Apart from the routine physical discomfort of having to wait to use the washroom, it is conceivable that social isolation among persons with sex-variances might be worsened by the inability to use public washrooms.

This is a site that is already ripe for social work intervention. The most readily available and versatile intervention is in the form of the single-stall washroom. Countless people, whether heteronormative or not, can make use of such amenities. Single-stall

washrooms are already welcomed by persons with physical disabilities, caregivers with small children, and a myriad of other people who may find traditional washroom arrangements to be less-than-accessible. In terms of feasibility, single-stall washrooms are already present in a variety of locales, such as shopping malls, service stations, hospitals, etc., such that there is no reason why their presence might not be handily expanded. Social workers who wonder what it is like to collaborate with such professionals as urban planners, architects and engineers, may wish to use the banner of promoting single-stall washrooms as an opportunity for such engagements. While there is a substantial volume of scholarly literature surrounding single-stall washrooms, far beyond what I can manageably cite here, this intervention is more or less common sense and does not demand the backing of peer review. Alternatively, social workers can do their best to help individuals with sex-variances adapt to using sex-segregated public washrooms as best as is possible given the circumstances. This may be a good site for social workers to conduct studies. This intervention has less potential than does promoting the single-stall washroom, but has merit nonetheless.

### **5.5 Self-identity**

Participants indicated that their having sex-variances influenced their self-identity. All participants identified with the label intersex. What was particularly clear is that atypical genitalia significantly impacted the identities of the affected participants. However, the presence of atypical genitalia was not problematic in and of itself. Rather, the problems that did occur were the result of the larger community upholding heteronormative values surrounding what genitals should or should not look like. Deception served to worsen matters. The damage caused to Carl's self-identity and self-

image when he found out that he had been lied to, and that he had been surgically altered without his consent, speaks to just how harmful this paradigm is. This speaks to the need for honesty and transparency from service providers to their recipients who have sex-variances. Deception does nothing to encourage a positive self-identity. In this context, the paradigm of non-consensual cosmetic genital surgery is akin to telling someone who is gay that they cannot "act gay in public". Social workers here can defend against the imposition of shame and stigma by other professionals, which can hinder self-identity development and ultimately lead to lasting harm.

Apart from the impact of atypical genitalia and other sex characteristics on the identities of the affected participants, no clear patterns emerge surrounding self-identity. Some participants identified as straight, some as gay. Most participants clearly identified either as typically feminine or typically masculine. The exception to this was Nick, who was more or less ambivalent to gender norms. To be sure, though, Nick had no reservations about living and presenting in a more or less masculine fashion. What this lack of uniformity speaks to is the diversity that occurs among individuals with sex-variances.

While Dina indicated having transitioned, she did not exhibit any propensity towards gender-variance or ambivalence, and this was not a part of her self-identity. A social worker working with a case like Dina's would need to be astutely aware of the fact that a desire to transition is not always indicative of gender-variance. This would need to be properly conveyed to the rest of the professionals working with her. The fact that her genitals were entirely irreconcilable with masculine standards, but corresponded with standards of femininity, speaks to the fact that she should have been raised as a girl. In

fact, Dina's self-identity was only threatened until she transitioned. Dina's case reaffirms the need for honesty and transparency by service providers. Once again, had the dialogue between Dina's doctor, and her and her father been more open, her doctor would have informed her of the option to live as a girl, and a great burden upon her could have been resolved years earlier than it was. This is a site where having a social worker advocate for Dina may have benefitted her self-identity a great deal.

Lastly, instilling upon service recipients that no one form of self-identity is any more or any less worthy than any other will help in building a positive self-identity. This may assuage any feelings of shame that service recipients harbor about themselves. This will also serve as a reminder to other health and medical professionals that it is imprudent to stereotype people with sex-variances, as there is substantial diversity within this population.

### **5.6 Intimate partner(s)**

Participants primarily spoke of having been in long-term relationships. On the one hand, long-term relationships are indicative of intimate stability and predictability. It may be the case here that individuals with sex-variances feel more strongly attracted to partners who are willing to accept them for who they are. However, long term relationships may also signify a "make do with whomever you get you can get, and stay with them for as long as you can" approach. In this case, there may be underlying fears of not being able to find another partner if the current relationship dissolves. This may be especially so for individuals with noticeably atypical genitals, who may have experienced intimate rejection or even humiliation as a result of their bodies. I note here that a "take what you can" approach may lend itself to an increased likelihood for intimate partner

violence. In the study, there were no participants who indicated exposure to intimate partner violence, but they may not represent the status quo. I would caution social workers here against imposing models of domestic violence used with gay, lesbian, and bisexual populations on people with sex-variances, as members of latter tend to identify more often than not as heterosexual. As for specific intervention strategies, I am at a loss. The matter of intimate partner violence among individuals with sex-variances is certainly a site ripe for inquiry and exploration.

While social workers may not be able to undo normative values surrounding intimacy, we can most certainly help individuals develop a balanced and realistic appreciation of their redeeming qualities. Such qualities can be used to help attract intimate partners. Here, as in other sites, individuals with sex variances may benefit from learning how to deflect shame and develop a greater self-image. People with sex-variances may further benefit from being reassured that they are in no way culpable for having bodies that that are atypical in some ways. While this may seem somewhat trite, the damage that internalized oppression causes cannot be understated. This goes back once again to overcoming shame, stigma, and frustration.

Nick's lack of sexual contact may reflect a sizable number of individuals with sex-variances. This situation may be the result of endocrinal atypicalities leading to a lack of sexual interest, surgery leading to less-sensate or insensate genitals, or an inability to acquire sexual partners due to such issues as fear, shame, stigma, or social isolation (Holmes, 2009; Morland, 2009). Nick spoke of obtaining satisfaction through exclusively platonic relationships, indicating adequate social functionality despite a lack of sexual capacity. For those with sex-variances who experience challenges due to a lack of genital

sensitivity, sexual interest, or sexual opportunities, social workers can help in finding alternative means of fulfillment. In designing research and interventions surrounding sex-variances and sexuality, social workers need to make sure that inquiries do not assume sex-normative standards from the outset. It should not be assumed that genital sensation or sexual interest exists in all persons with sex-variances. Nor should it be assumed that these do not exist at all. This is a site that invites social workers to engage in sex-variance advocacy through opposing non-consensual cosmetic genital surgeries.

### **5.7 Family**

This was by far the most emotionally charged section of each interview. At times, there were tears and feelings of distress. The big message here was that participants were unhappy with, and even resentful of, the lack of information from their families in relation to their sex-variances. Deception was a catalyst for much, if not all, of the turmoil participants experienced with their families. What was central to both the withholding of information and the deception, was that it was the result of either poor advice or inaction on the part of medical doctors. It is probable that if doctors told parents to be forthright and honest with their children, instead of telling them to conceal the truth about their children's sex-variances, that the upset that was discussed would have been of a much lesser degree or even nonexistent.

Social workers need to do their best to cultivate harmony within the family unit. This helps to ensure that the best interests of children are met. Part of this task can be achieved by fostering honesty and transparency from families and the involved professionals alike. Social workers can play an educational role in helping to make sure that families know how to go about telling the truth to children when they are old enough

to understand and appreciate what having a sex-variance means. As health and medical professionals may be the primary source of support for families of children with sex-variances, it is important that such families can observe these professionals engaging in the same levels of honesty and transparency that is expected of them. Social workers may facilitate open dialogue between all of the involved service providers, and also between service providers and service recipients or families.

It is possible in some situations that social workers may not become part of the multidisciplinary team until after deception and the withholding of information has caused resentment to form. Here, providing family counseling services may allow families to lay all the cards on the table and to share the reasons why they used deception. It may allow opportunities for families to apologize to, and to reconcile with, their children with sex-variances. It may allow opportunities to rekindle the familial relationship through moderated discussion.

If participants had social workers to make sure that they were told the truth of their sex-variances and told of all of their options, I am sure they would have very different stories to tell. If somebody in the same situation as Dina's father had the know-how to explain to their child what options were available, instead of trying to persuade a resistant physician to do this, then this may serve to prevent years of anguish. Here, social workers may wish to provide educational supports to families of children with sex variances, explaining to families how to collaborate with their children in figuring out the best courses of action that best serve the children's interests.

## 5.8 Peers

Participants did not speak at all about their peer situations as adults, so I have no analyses to make in this regard. I think that this is an area in need of further research. When I asked participants to tell me about their experiences with peers, they spoke in terms of their childhoods, and I did not specifically ask about their peer experiences as adults. In terms of their peer situations as children and youths, participants all had a fair deal to say. The key feature was that the further away from sex-normative archetypes participants were, the more they experienced alienation and isolation, and the less positive experiences they had interacting with peers. Negative experiences led to increased frustration. Participants found interaction easier when peers were unaware of their sex-variances. This is a double-edged sword. On the one hand, shame and stigma fester when people are forced to conceal the truth about themselves. Here, there is a risk of internalizing negativity, and of thinking that shame and stigma are somehow justified. In this case, social workers may wish to utilize esteem-building and shame/stigma-resisting strategies that are appropriate for the situation. On the other hand, having everyone know about their sex-variances, with rumors and gossip circulating, caused shame and stigma to worsen just the same. Here, there is a risk of bullying that became all too real for each of the study participants. In this case, social workers may wish to employ anti-bullying and ally-building strategies. Further, social workers may also wish to help young service recipients learn how to better assess who it may be safe to disclose the fact of their sex-variances to, and how to determine opportune times for doing so.

Given the relatively small proportion of children with sex-variances, allies are likely to be a key factor in successful peer networking outcomes. I think the three pillars

model is particularly valuable here, as it may be conducive to generating a sense of commonality between the groups it encompasses. While heterosexual-identified children and youths with sex-variances may have substantially different concerns than children and youths who are gay, lesbian or bisexual, I think that it may be possible for organizations developed by and for LGBT populations to be mindfully inclusive of people with sex-variances. For example, capacity building within Gay-Straight Alliances (GSAs), which currently have chapters in a number of schools (Miceli, 2005), may allow such groups to expand their mandates so as to be expressly inclusive of people with sex-variances. Such mandate-expansion may allow GSAs to attract members from within all of the three pillars of sex, gender, and sexuality, as well as allies. This may afford safe and affirming spaces for children and youth with sex-variances to be more open about their situations. This in turn may generate greater opportunities for positive peer interactions by everyone involved.

### **5.9 Sex-variance community and capacity-building**

The idea of community is diverse, complex, and multifaceted. Maclaran & Catterall (2002) discuss online communities, which are starkly different from communities in the traditional sense. Clark (1973) discusses community in terms of locality, social activity, social structure, and sentiment, with a sense of both solidarity and significance as core components (p. 397-404). For Wiesenfeld (1996), a community consists of a "group of people who share a set of common features" and "is built upon individuals' needs, social relationships with their emotional concomitants, networking or the exchange of material resources, [and] psychological issues ... as well as social issues" (p. 339). In discussing the sex-variance community, I am referring to an

abstraction with a myriad of permutations and not to a single cohesive thing. This could mean any number of things, depending on the context. The sex-variance community is thus shorthand for any given aggregate of sex-variance organizations or individuals with sex-variances.

There are a number of sex-variance organizations, with most research participants belonging to one or more of them. These participants felt a sense of belonging, and were glad to be part of collective organizations that allowed them to meet other like-minded and like-bodied people. Dina was an exception. She was skeptical about the idea of a sex-variance community and leery of sex-variance organizations. She felt that the animosity between factions was a substantial barrier to them working together. Based on participant inputs here, social workers may wish to help service recipients connect with relevant sex-variance organizations. These organizations may help in addressing or avoiding shame and stigma through collective action, and may offer opportunities for both socialization and advocacy, helping individuals with sex-variances to overcome isolation. Some organizations will be helpful to some individuals while others will not. It is important to not idealize organizations and to recognize that there are often competing political approaches and even conflicts within and among these organizations.

As it is not my purpose in this thesis to endorse any organizations over any others, I will not mention any names here. Some of these organizations are narrowly-focused support groups whose members have one particular sex-variance, or a narrow range of closely related sex-variances. Other organizations are advocacy groups that address concerns held by people with sex-variances in general. Still others are clinically-oriented

organizations that collaborate with health and medical professionals in developing the most mindful, respectful, and effective interventions possible. Some of these organizations have radically different philosophies that make them irreconcilable with one another. Other organizations, however, may be very amiable to one another, and may even share staff and board members in common. It is these latter groups that social workers may wish to focus their capacity-building endeavors on. I note that some of these organizations already list a number of social workers on their staffs and boards of directors, possibly making them more readily contactable by other social workers.

## **Chapter 6: Conclusion**

To reiterate, my goal in writing this thesis was to identify and explore some of the themes and issues that members of the social work profession may wish to consider when investigating matters pertaining to the wellness of individuals with sex-variances, or in making recommendations about working with individuals with sex-variances. While no definitive conclusions emerged from this exploratory research, the findings that did emerge may help guide the way to future research surrounding sex-variance wellness and the need for greater awareness and education among social workers. I utilized the qualitative approach of Interpretative Phenomenological Analysis. This method was well suited to this exploratory research as it emphasized the importance of the participants' experiences and my interpretations and analysis of the data collected. I found IPA useful in that it allowed me to present participants' words in an interpreted form accessible to social workers and other health and medical professionals. Further, I found an insider perspective to be helpful. Firstly, it allowed me to establish better rapport with participants during both the recruitment stage and the interview stage, in that I did not come across as an interloper in the way that an outsider may. Secondly, it allowed me to handily design the topics to be discussed during the interview, as I knew ahead of time some of the areas that participants may want to address.

Next, I defined wellness as quality of life in a holistic biopsychosocial manner that is consistent with common social work practice approaches. After this, I defined sex-variances and discussed some of the past and contemporary nomenclature involved. Further, I defined sex, gender, and sexuality, and then defined heteronormativity as a dominant ideology in relation to these three interconnected facets of human experience. I

indicated that heteronormativity fabricates an unjustified ideological demand for non-consensual cosmetic genital surgery, which is often imposed on individuals with sex-variances. I argued that such surgeries are based on an erroneous mismatching of sex-variances and gender-variances, whereby the mere presence of atypical genitals is mistakenly held to cause psychological instabilities. I asserted that non-consensual cosmetic genital surgeries deny the self-determination and informed consent of individuals with atypical genitals, often with debilitating and disfiguring results. Further, I indicated that while some sex attributes can be modified to a certain degree, that sex is too complex to be wholly manipulated. As such, I argued that sex (re)assignment is a misnomer, and that non-consensual cosmetic genital surgery is entirely futile. I lastly argued that heteronormative ideology needs to be confronted in order to combat the imposition of non-consensual cosmetic genital surgeries on individuals with sex-variances.

In formulating a broad-based resistance strategy against heteronormative ideology, I laid out what I refer to as the three pillars model. I posited this model, encompassing diversity of sex, gender, and sexuality, as a way for the involved, oft-contrasting populations to stand together against a common oppressor. Rather than positioning sex, gender, and sexuality within a larger intersectionality perspective, I argued that doing so could serve to dilute and distort the genuinely oppressive effects that heteronormative ideology has on these three pillars. In discussing the three pillars model, I cautioned that sex-variance populations are not LGBT subsets. However, I noted that sex-variance populations may wish to seek alliances with LGBT populations, given the significantly greater numbers and access to resources on the part of the latter.

Next, I commenced with a review of both earlier and contemporary literature surrounding sex-variances. I began with a review of some of the work of John Money, who gained notoriety with his socially-centred perspectives. Next, I reviewed the Chicago Consensus, which utilizes an evidence-based approach favoring empirical inputs over unsubstantiated ideologies. Lastly, I reviewed the ISNA clinical guidelines, which were formulated by a sex-variance advocacy organization, and designed for use by interdisciplinary teams consisting of a variety of health and medical professionals. I then moved on to discuss the study methodology.

The purposive approach of criterion-snowball sampling was valuable for use with the hard-to-reach population involved in the study. In terms of research design, the formal process was divided into three stages: data collection, data codification, and interpretative analysis. Data collection took the form of semi-structured interviews, with schedules consisting of a few general topics for discussion. The main limitation of this research was that the study findings were not generalizable to the larger population of individuals with sex-variances, but relevant only to the participants themselves. However, while the findings were not generalizable, this study may nonetheless help to shape future research by providing a framework for issues needing to be addressed, for questions needing to be asked, and for the sort of responses that are needing to be sought out. For example, this research showed shame, stigma, and frustration as major barriers to sex-variance wellness that have a common antecedent of heteronormative ideology. Here, heteronormativity is revealed as a foundational issue in negative wellness outcomes among individuals with sex-variances.

Overall, the IPA method was useful in gaining an overview of the experiences of wellness among individuals with sex-variances. Here, qualitative data, including phenomenological data, is required for understandings relating to thoughts, feelings, desires, and other intangible aspects of wellness. However, future research employing quantitative data may assist in measuring, for example, the prevalence of suicidality or diagnosable mental illnesses among individuals with sex-variances. Standardized measures may allow for assessments of such things as depression, anxiety, or hopelessness among this population. Future research adopting multiple methods may allow for different focuses supported by the strengths of both qualitative and quantitative data.

Central themes emerging from this study include medicalization and overmedicalization, shame and stigma, and frustration. I want to be clear that sex-variances are genuine medical conditions. The problem lies not in the fact that sex-variances are merely seen as medical conditions (i.e., medicalization) but that they are subsequently viewed through a heteronormative lens, with the end result of oppressive interventions that transgress the scope of medicine and the other involved health and medical practices (including social work). Here, medicine is turned from an agent of wellness into an agent of social control (i.e., overmedicalization). A clear example of this social control is found in the practice performing non-consensual cosmetic genital surgeries.

Often, however, the line between medicalization and overmedicalization is less than clear. The distinction between where atypical ends and pathology begins is oft-hazy. Tension arises in differentiating between what needs to be done to help service recipients,

and what amounts to overreach. Medicalization is further complicated through being distorted by heteronormative ideology. This ideology drives medical overreach and overmedicalization by making things otherwise extraneous to medicine, such as atypical genitalia or same-sex attractions, into medical crises. Once heteronormativity is infused into medicalization, overmedicalization spreads to the point that harmful interventions such as non-consensual cosmetic genital surgeries and gay-aversion therapy become status quo. I can offer opposition to heteronormative ideology in the form of the three pillars model, but I simply cannot solve the dilemma of medicalization—overmedicalization in this thesis. All I can recommend here is that social workers, and other health and medical professionals, be vigilantly mindful of their scope of practice, their ethical principles, and their desired practice outcomes in the context of sex-variances. This goal can be advanced through acquiring a greater wealth of knowledge surrounding what exactly sex-variance wellness entails and how to go about achieving it, an exploration of which I have provided in this thesis.

I argue that cosmetic surgical procedures should never take place unless at the behest of, and with the explicit informed consent of, the individual on whom the procedures are to be performed. Non-consensual ablation of viable tissue in the pursuit of cosmetic ideals is mutilation. It represents the antithesis of what health and medical professionals are supposed to represent, namely the wellness interests of the individuals they serve. The best that health and medical professionals can do is to employ evidence-based anti-oppressive interventions that serve to empower people with sex-variances and their families. However, surgical procedures may sometimes be necessary to address threats to physical health, such as the presence of cancerous tissue that may be associated

with AIS (ADAM, 2012b). Similarly, pharmacological interventions may be necessary, such as in the case of salt-wasting CAH (ADAM, 2012a).

Shame and stigma had detrimental effects on all participants. More in-depth understandings of the way heteronormative ideology impacts both those victimized by it, and society as a whole, will shed light on how shame and stigma affects individuals with sex variances. After all, it is heteronormative ideology which drives shame and stigma surrounding sex variances. Once we have the necessary information, we can decide what to do in response. This is by no means a new issue, and we can rely on existing literature and interventions to guide us from here. I think the three pillars model may be of substantial value here, as it may be used to facilitate a power-in-numbers approach to confronting heteronormativity through building bridges beyond the sex-variance sphere. Approaches based on the three pillars model may draw more unified numbers and resources to confront heteronormativity and the ills that stem from it.

The frustration expressed by participants in the study was largely the result of the shame and stigma they had experienced. Having shame and stigma all around, and having no one whom you trust to turn to, causes frustration to steadily grow. This is a site ripe for social work intervention. As social workers, we are well-equipped to deal with shame, stigma, and frustration – this is right up our alley. Lastly, this study revealed findings in relation to participants' experiences with public washrooms, self-identity, intimate partners, family, peers, the supposed sex-variance community, and the larger community. All of these themes are prime sites for further research by social workers.

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## **Appendices**

### **Appendix 1: Recruitment Form**

Greetings!

My name is Mórrígan Wolf and I am a Master of Social Work candidate at Dalhousie University in Halifax, Nova Scotia. I am currently organizing a study titled Exploring Intersex Wellness and would like to invite you to help me recruit participants. I am looking to conduct a number of confidential one-on-one interviews with adults who have sex-variant (intersex) physiologies. The interviews, each of which will last for approximately two hours, will take place in person at safe locations that are agreed upon by both the participants and me. The interviews will be scheduled for sometime in Feb/Mar 2012. Participants will be given a twenty five dollar cash honorarium to cover any expenses they may incur as a result of their participation, such as transportation, babysitting or parking.

During the course of each interview, I will ask participants to talk about their experiences with a number of things, such as the health system, the education system and their communities, and to tell me how improvements can be made in each area. The objective of this study is to explore the lived experiences of participants, in their own words and through their own voices. This study will help in gaining a better understanding about how to meet the wellness needs of persons with sex-variant physiologies in ways that they themselves want to see happen.

If you know anyone who you think may wish to participate in this study, or if you know anyone who you think may be able to help me recruit participants, kindly ask them to email me at: [mr380180@dal.ca](mailto:mr380180@dal.ca).

## **Appendix 2: Consent Form**

My name is Mórrígan Wolf and I am a Master of Social Work candidate at Dalhousie University in Halifax, Nova Scotia, Canada. You are invited to take part in a research study, titled Exploring Intersex Wellness, that I am conducting as part of my Master of Social Work thesis. Your participation in this study is voluntary and you may withdraw from the study at any time. The study is described below. This description tells you about the risks, inconvenience, or discomfort which you might experience.

Participating in the study might not benefit you, but what is learned might serve to benefit others. Participation in this study is limited to persons with sex-variant (intersex) physiologies who are eighteen years of age or older. If you participate in this study, you will be given twenty-five dollars cash to cover costs such as babysitting, transportation or parking, that you may incur as a result of your participation.

The purpose of this study is to learn first-hand about the experiences that persons with sex-variant physiologies have with such things as the health system, the education system, their families and their communities, and the ways in which these experiences could be more respectful and empowering. The study involves interviews with up to fifteen participants. The things that the participants say will be explored for common themes, which will then be spelled out in ways that helping professionals such as doctors, teachers, counsellors and social workers, can make sense of and put to use. It is hoped that what is said in the interviews will be able to guide helping professionals in working with persons with sex-variant physiologies in ways that are truthful and forthcoming, and which allow persons with sex-variant physiologies themselves to have the final say in how they are treated. It is important for you to know that I am not a neutral observer in

this study and that I will interpret the findings with methods that utilize my own experience, values and understandings. Further, the findings from this study may be used for political purposes, such as intersex advocacy, policy and legislation advisory, or shaping how helping professionals deliver services to persons with sex-variant physiologies, and may not be in accord with your own personal views.

I am the primary researcher involved in this study, and I will be conducting all of the interviews and interpreting all of the results. Dr. Catrina Brown, of the Dalhousie University School of Social Work, will be the supervisor for this study. Dr. Brown will be providing guidance to me throughout the course of the study and will evaluate the final results of the study. Only I and Dr. Brown will have access to the audio recording and transcription of your interview.

If you decide to participate in the study, I will meet with you for a one on one interview that will take place in a private and safe location that you and I both agree to ahead of time. The interview will be audio recorded with a digital voice recorder and transcribed at a later time.

During the interview, you will be asked to talk about your experiences with such things as the health care system, the education system, your family and your community. You will also be asked for your input on what you feel helping professionals could do to better serve people with sex-variant physiologies. The exact details of the interview will depend on what you decide to talk about. The interview will last approximately two hours, but may be longer or shorter depending on the topics covered and the depth to which you wish to discuss them.

Although you may not personally experience any benefits from participating in this study, it is possible that other people may benefit from it. In particular, this study may be able to provide helping professionals with a greater understanding and awareness of the needs of people with sex-variant physiologies, which may in turn serve to benefit everyone involved.

There is a risk that you may experience discomfort or become upset while discussing some of your experiences. The anticipated level of discomfort or upset involved in this study is not greater than what you might typically experience in your daily life as a person with a sex-variant physiology and the risk to you is minimal.

There is a risk that your participation in this study may become known, and, unless you are openly intersex identified or otherwise openly identify as having a sex-variant physiology, your having a sex-variant physiology may subsequently become known as a result. The protocols that I observe to maintain confidentiality, such as the utilization of secure Internet transmission of files that are password-encrypted and subsequently uploaded to my password-protected account at Dalhousie University (where only I know the passwords in question), will help to minimize the likelihood of this happening.

This study will uphold your confidentiality. What you say during your interview will not be linked to your name in any way. The names of people and places that you talk about during your interview will not be mentioned in the study report. You will be assigned an ID number that will be used in place of your name on this consent form and on the receipt for the twenty-five dollars you will receive for participating in the study, both of which need to be signed by you. This ID number will not be linked in any way to

your voice recorded interview. The consent form and receipt will be scanned, and the paper copies will be destroyed as soon as possible after your interview.

While this study is underway, all of the documents associated with it will be stored either online in my password protected account at Dalhousie University, or on my password-protected computer, to which only I have access. When this study is complete, all of the documents associated with it will be stored password-encrypted (only I will know the password) for five years on DVDs that will be held in a locked filing cabinet belonging to Dr. Brown. When five years have passed, the DVDs will be destroyed. The thesis which details the findings of this study will be archived by Dalhousie University. This thesis may also be published elsewhere, in whole or in part, at my discretion.

I will protect your confidentiality to the best of my ability. However, if you reveal to me during your interview that abuse or neglect is currently happening to either a child or to an adult in need of protection, then I am obliged to inform the appropriate authorities about this and to give them your name if required to do so by law. Note that this only applies to abuse or neglect that is currently happening, and does not apply to abuse or neglect that happened in the past.

If quotes from your interview are used in the thesis which details the findings of this study, they will be used in a manner that does not risk revealing your identity. In particular, you will be attributed as 'a participant' rather than by name, the names of people will be reworded so as to be generic in cases where their use may identify you or may pose a risk to the person being named, and the names of specific places will be reworded so as to be generic in cases where their use may identify you.

If you have any questions about this study, you should take them up with me. You can contact me by email at [mr380180@dal.ca](mailto:mr380180@dal.ca). If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Catherine Connors, Director, Research Ethics, Dalhousie University, by phone at (902) 494-1462 or by email at [ethics@dal.ca](mailto:ethics@dal.ca).

In signing this CONSENT FORM, I agree to the following:

- I have read and understand the contents of this CONSENT FORM.
- I consent to participate in an audio recorded interview with Mórrígan Wolf.
- I consent to have both my audio recorded interview and the documentation associated with it stored online through Dalhousie University, and transcribed and analysed in Halifax, Nova Scotia, Canada.
- I consent to the use of quotes as outline in this CONSENT FORM.

Participant Signature/Date \_\_\_\_\_

Researcher Signature/Date \_\_\_\_\_

### **Appendix 3: Interview Guide**

This interview will cover the following topics in answering the question "what does wellness mean for persons with sex-variant physiologies?":

- Experiences with and comments about the health system.
- Experiences with and comments about the child protection system.
- Experiences with and comments about the education system.
- Experiences with and comments about the legal system (courts, corrections, vital statistics).
- Experiences with and comments about parents/family.
- Experiences with and comments about social networking.
- Experiences with and comments about the community at large.
- Experiences with and comments about romantic/intimate relationships.
- Experiences with and comments about the workplace.
- Experiences with and comments about identity formation, particularly in terms of sex, sexuality and gender.
- Comments about how persons with sex-variant physiologies and their interests could be better protected.
- Comments about how persons with sex-variant physiologies could be better listened to and provided with all of the information relating to their situations.

The following is a sampling of questions that may be asked in the interviews surrounding what are likely to be the most dominant themes:

### Health

- How were you treated by the health system? Are there particular aspects of that system that worked for you?
- Did the health system invoke secrecy or shame surrounding your being a person with a sex-variant physiology? What would you like to have done so as to have made your experiences more empowering?
- If you could design a specialized health division to address sex-variant physiology in a manner that you feel would be for the best, what things would it be able to do and how would it go about doing them? What kinds of specialists and professionals would be there, what would they do, and how would they go about doing it?

### Education

- What was your experience with the education system like? Were teachers and guidance counsellors able to accommodate your needs?
- Did you feel ostracized and if so, what could have been done to improve things for you?
- What do you feel were the best and worst aspects of the education system, and what could have made it better?

### Parents/family

- How did your parents/family deal with your intersexuality? Did they hide things from you or were they forthcoming? How old were you when they told you, or did you find out on your own?
- Do you feel that they accept you for who and what you are?
- If you could go back to when you were first born and give some advice to your parents/family, what would you say?

### Community

- How do you feel the community at large views intersexuality? What could be done to improve this? What can communities do be more inclusive of intersex people?
- How have you been treated in the communities you have lived in? Do you feel that you are accepted by your community?
- Do you feel that there is an intersex community to which you belong? Is this something that might interest you?

### Sex, sexuality and gender identity

- How do you identify in terms of your sex, your sexuality and your gender?
- Do you feel that your rights are protected and respected?
- What do you feel should be done in order for your world to be more inclusive of people who identify as you do?