# **Guest Editors' Introduction**

Trans Rights as Human Rights: The Implications for Trans Health (Care)

[E]ven the most cursory examination of health in daily conversation, email solicitation, or media representation demonstrates how the term is used to make moral judgements, convey prejudice, sell products, or even to exclude whole groups of persons from health care. (Metzl and Kirkland 2010, 2)

IN THEIR 2010 anthology, Against Health: How Health Became the New Morality, Metzl and Kirkland highlight how contemporary understandings of health have come to permeate every aspect of daily life, shaping lived, bodily realities, and playing an important role in determining which lives are visible and viable. Understandings of "health" and "illness" change over time due to developments in medical and scientific knowledge, and to changing cultural norms about the healthy body and mind (Foucault 1979; 1991; Canguilheim 1989; Metzl and Kirkland 2010). This finds concrete, contemporary form in international guidelines such as the International Classification of Diseases (ICD) and the Diagnostic and Statistical Manual of Mental Disorders (DSM), periodic revision of which invariably provokes lively debate. These changes take place as part of broader sociocultural shifts in understandings of the "healthy" body and mind. In practice, bodies and minds that comply with surrounding norms are less visible than those that fail to do so (Leder 1990; Shildrick 2002). "Healthy" bodies and minds are those perceived to "fit in" to their surroundings; those who do not comply are more visible in their difference, and thus more often more subject

to management or surveillance. Against this background, this special issue focuses in on the normative power of health (care) in the specific context of trans<sup>1</sup> health (care). As such, this special issue also takes inspiration from recent reports published by the Swedish National Board of Health and Welfare (Socialstyrelsen 2010), the Swedish Federation for Lesbian, Gay, Bisexual and Transgender Rights (RFSL 2011), and the World Professional Association for Transgender Health (WPATH 2011) that highlight particular challenges for trans persons in relation to health (care).

#### Trans Health: An Overview

The field of trans health studies is a comparatively young field. The first male to female surgical transformation happened in Germany in the 1930s, while the first female to male reassignment surgery took place in New Zealand in 1946. Harry Benjamin, one of the best-known physicians for trans persons, formulated his (now much debated) "Standards of Care" in 1979. The requirement for a medical diagnosis of gender identity disorder has led to trans people being heavily scrutinised by the medical community who function as gatekeepers, controlling access to the various stages of psychological, hormonal and surgical treatment which form the current path to transition. This diagnosis also has the broader effect of stigmatizing and pathologizing trans persons, as well as implicitly reinforcing the notion of a clearly defined gender binary. It is only in recent years, and connected to queer understandings of identity, that a more complex understanding of gender identity, often expressed through identities such as "genderqueer," has emerged.

Research to date on health care for trans people could be loosely organised into three groups: 1) that produced by health care professionals who provide treatment to transsexuals; 2) that produced by health care professionals reflecting on the standards and quality of care available for trans persons; 3) that produced by critical theorists and activists which embraces a more fluid understanding of gender identity. The first group includes work done within fields such as sexual medicine (Nieder et al. 2011), counselling and therapy (Franzini et al. 1977), psychiatry (Freed-

man et al. 2002), surgery (Gilbert et al. 1988), and endocrinology (Lombardo et al. 2013). These studies focus on advancing medical knowledge around specific procedures and often implicitly pathologize trans people. In common with the dominant medical paradigm these research papers use an impersonal tone and present their results as universally applicable, rather than reflecting on specificities of the local context such as legal frameworks or medical insurance.

The second group of scholarship that we want to highlight here concerns the quality of health care available for trans persons. This, in contrast, tends to be clearly focused on the affordances and limitations of particular local contexts, for example health care for trans persons in Finland (Pimenoff 2006). The contingency of these studies clearly demonstrates the entanglement between legal and medical practices that has long resulted in cross-border travel for transition (see, for example Jan Morris' Conundrum first published in 1972 or April Ashley's biography, Odyssey, published in 1982. For more recent examples, see Griggs 2004 or Aizura 2010). Related work includes that which offers advice to primary care physicians on how best to provide health care to a trans person (Feldman and Goldberg 2006). It is recognised in this literature that experiences of transphobia and discrimination in the health care sector may lead to avoidance of medical care by trans persons (Kammerer et al. 1999), and the population is recognised as an underserved one (Feldman and Goldberg 2006). These studies show a move from disease-based understandings of trans towards an identity-based model (Feldman and Goldberg 2006; Bockting 2009). Increasingly a paradigm organised around "patient-centred" (Speer and McPhillips 2013) or communityidentified treatment needs is now emerging, epitomised by organisations such as the Center of Excellence for Transgender Health in San Francisco. Centres like this are also significant in that they work with a bigger picture of trans health needs that encompasses, but also moves beyond, the transition process itself.

The final grouping spans work from fields such as feminist theory, somatechnics, body studies and queer studies. This scholarship tends to draw attention to the entanglement of corporeal realities, discourses,

and technologies. This body of work highlights the power dynamics in play which determine access to health care and which depend upon the correct bodily and narrative performances in order to "fit in" with the received story of transition. Overall, it takes a critical perspective on the assumptions, norms and gatekeeping inherent in so many aspects of health care related to trans lives. It is here that debates on queer understandings of identity which challenge binary understandings of gender have appeared. The work in this group is also remarkable for its interdisciplinarity and its range, spanning theoretical discussion (Butler 2004), technoscientific critique (Stone 1998), historical account (Meyerowitz 2002), artwork (Volcano and Windh 2005), fiction (Carter 1977), and semi-personal narratives (Feinberg 1993), to name just a few.

Whilst by no means a conclusive overview of trans health, the broad groupings of scholarship suggested above highlight the very different perspectives afforded by different disciplinary positions, as well as the move from doctor-, to patient-, to community centred health care. The differing priorities of the various people and institutions involved continue to raise questions around topics that affect the lives and wellbeing of trans people. It is also worth noting the importance of, and need for, more research conducted within specific regions that highlights the differences in experiences, access and treatments.

Contemporary research from the Nordic region, for example, investigates specific regional circumstances in relation to trans rights, anti-discrimination work and improvement of trans health, health care and treatment. This work achieves two things: first, knowledge of, and competence on, specific Nordic circumstances are collected (compiling governmental reports, trans politics and research), and secondly, through this work, there is an increasing emphasis of trans rights. Regional perspectives make an important contribution to knowledge production surrounding trans lives, furthering trans perspectives and functioning as inspiration for additional research and political work.

Nordic trans studies related to health care can be loosely organised into three groups: 1) medical research; 2) studies specifically oriented towards trans health care; 3) descriptive, qualitative ethnographic and cultural

studies. Trans health care can benefit from research done in all of these categories, as increased knowledge and visibility of particular circumstances are a prerequisite for developing better health care conditions.

The first group comprises medical research conducted by health care professionals, and focuses mainly on follow-up studies and aetiology (attempts to find an explanation for gender identity disorder). Follow-up studies have measured the rated outcome and well-being of those who have undergone sex reassignment surgery (SRS) (Wålinder et al. 1975; Sørensen 1981; Lundström et al. 1984; Lindemalm et al. 1986; Bodlund and Kullgren 1996; Eldh et al. 1997; Johansson et al. 2009, as well as an ongoing doctoral project by Dhejne, Karolinska University Hospital). The evaluation includes surgical and hormonal treatment outcomes, level of regrets, and global functioning according a standardized scale that investigates employment situation, financial situation, partner, family and other relations, sexual functioning and orientation, physical and mental health (see Johansson et al. 2009). One study, however, that measured both clinicians' and patients' views on outcome and wellbeing after SRS concluded that patients' self rated views on outcomes were much better than the clinicians rating (Johansson et al. 2010), pointing to potential problems in measuring wellbeing on a standardized scale. Aetiology studies in this field also highlight problems with rigid or proscriptive categories in that they tend to reinforce normative gender binaries (Landén 1999; Berglund et al. 2008). Further examples of medical research in the Nordic region are rather diverse, covering male transvestism (Larsson and Bergström-Walan 1992; 1999; Larson 1997), one follow-up study on cases not accepted for SRS (Lundström 1981), the prognostic factors of transsexualism (Wålinder et al. 1978; Lindemalm et al. 1987; Bodlund and Kullgren 1996), and descriptive and psychological studies (Lundström 1981; Larsson and Bergström-Walan 1992; 1999; Larson 1997; Bodlund 1994).

The second group includes research on trans health conducted by non-medical professionals. Some of the work is specifically focused on the practices, treatment and conditions of trans health care, while some addresses issues with relevance for trans health care such as em-

bodiment, body and trans politics. Trans politics promotes change and improvements in trans treatment and health care, incorporating both legal changes and social changes in attitude and recognition of gender variance (Engdahl 2011). To date, this has involved both descriptive studies and advisory studies regarding trans rights, or what trans justice can mean, especially in relation to trans health and health care (Wickman 2001; Engdahl 2011; van der Ros 2013a; 2013b; Sørlie 2013). Other notable examples include an ongoing doctoral research project into the medical history of bodily modifications in the 20th century (Holm, Linköping University), as well as completed work on body politics within three Swedish governmental investigations (into gender reassignment, abortion and sterilisation) in the 1960s and 1970s2 (Alm 2006), contemporary access to gender reassignment treatment (Bremer 2011), and hormonal treatment and the performativity of sex hormones (Irni 2013). These studies take a critical perspective on the reproduction of binary gender norms within medico-legal contexts. Two further strands of work and activism are worth noting in this group: 1) trans knowledge and competence within organisational contexts which promotes trans inclusion and representation (Huuska 2002; Lehtonen 2002; Thanem 2011); 2) research on trans youth, with particular reference to debates on the age limit for access to gender reassignment (Statens folkhälsoinstitut 2006; 2008; Darj and Nathorst-Böös 2008; Socialstyrelsen 2010; Ungdomsstyrelsen 2010).

The third group of research conducted by scholars in the Nordic region is more varied, consisting of qualitative work on trans lives which offers insightful narrations of gender variance from biographical accounts, interview studies and cultural representations. These forms of knowledge production create a foundation of trans knowledge that is based on a nuanced understanding of trans lives and contributes to building up trans competence more generally. This work includes both completed and ongoing studies on relations between trans persons and their close relatives (Bergström 2007), female expressions of maleness (Kroon 2007), gender expressions and self-reflexivity on the internet (Berg 2008), trans screen births in video blogs on the internet (Raun 2012), drag king culture

in Sweden (Olovsdotter-Lööv, Lund University), drag shows and resistance against heteronormative power and norm structures with the help of different aesthetic strategies (Westerling, Stockholm University), trans representations in movies (Straube, Linköping University), and trans representations in Swedish literature (Holmqvist, Uppsala University). Some of this work is conducted within a general LGBT spectrum, which means that trans issues are covered as one perspective or strand along with others on the LGBT spectrum, for example elderly LGBT people (Siverskog, Linköping University), LGBT from a theological perspective (Gårdfeldt 2005), and trans and queer developments in theology (Forsberg, Uppsala University).

The body of work that we have sketched above highlights the important contributions to be made to trans knowledge production by the inclusion of regional perspectives, in this case the Nordic region. It also makes it possible to identify "gaps" where less research to date has been done. For example, it is notable that there is a lack of interdisciplinary research in the Nordic region on trans health (care) that brings together perspectives and expertise from health care professionals, researchers and activists. We hope that this special issue will play a small role in stimulating the development of such research.

## **Human Rights and Trans Health**

This notion that health care is the crux of livability in many different ways was what prompted us to organise the 2012 Trans Rights as Human Rights – The Implications for Trans Health (Care) conference. Both that conference and this special issue take as a starting point the recent United Nation resolution that affirms human rights to trans persons (TGEU 2011), and brings attention to human rights violations based on gender identity. Our aim at the conference, and in this special issue, is to focus specifically on the health care context as a key space in which issues of rights, responsibilities and care are highlighted.

When used as a strategy for change, and as a way to highlight how people are being unfairly treated, rights clearly have political force. However, implicit within the concept of rights is often a requirement to comply with certain social ideals or norms, in this case: binary gender norms. The theme of "trans rights as human rights" therefore conveys an ideal of human dignity specifically in relation to trans persons, with the particular experiences, life conditions, and needs of trans lives in mind. Interpreting rights in relation to specific contexts is a necessary procedure for the implementation of human rights. Doing so also paves the way to improved essential practices and services such as health care. This spirit is epitomized by documents such as the Yogyakarta principles, a document based on the UN's declaration on human rights applied to sexual orientation and gender identity. The document was formulated in 2006, when a distinguished group of international human rights experts met in Yogyakarta, Indonesia, with the aim of producing a set of human rights principles in relation to the particular circumstances of sexual orientation and gender identity:

Everyone has the right to recognition everywhere as a person before the law. Persons of diverse sexual orientations and gender identities shall enjoy legal capacity in all aspects of life. Each person's self-defined sexual orientation and gender identity is integral to their personality and is one of the most basic aspects of self-determination, dignity and freedom. No one shall be forced to undergo medical procedures, including sex reassignment surgery, sterilisation or hormonal therapy, as a requirement for legal recognition of their gender identity. No status, such as marriage or parenthood, may be invoked as such to prevent the legal recognition of a person's gender identity. No one shall be subjected to pressure to conceal, suppress or deny their sexual orientation or gender identity. (Article three of the Yogyakarta principles 2006)

Access to medical services, either for the purposes of transitioning or for other medical needs, has long been a contested and testing point for trans persons and their loved ones. Interactions with medical professionals represent an entanglement of medical, legal and financial power dynamics in which gaining access to medical services is either complicated through the lack of knowledge amongst medical professionals, or explic-

itly requires compliance with a received narrative based on assumptions about trans persons. Compliance is simultaneously a necessity in order to access services and a pathologizing manoeuvre which polices non-normative gender performances, rendering certain bodies and lives open to increased surveillance and intervention. Those who cannot, or will not, subscribe to the received medical narrative surrounding trans lives may be relegated to a kind of bureaucratic and medical limbo in which access to health care may be further delayed or problematized. As such, the health of trans persons and notions of what constitutes a "healthy" trans person can be considered a key aspect of human rights debates.

It is perhaps no surprise, then, that recent years have seen several major international debates centred on the medical definitions of trans, its de/pathologization, and the implications of this in terms of accessing and being able to afford health care. These include (but are not limited to) the revision of the *Diagnostic and Statistical Manual of Mental Disorders*, the Argentinian law on gender identity, and the controversy surrounding sterilisation in Sweden. In this special issue we are pleased to present a selection of contributions to these debates from both activists and academics.

#### The Contributions

This special issue opens with Josephine Krieg's article, "A Social Model of Trans and Crip Theory Narratives and Strategies in the Redefinition of the Pathologized Trans Subject". In this, Krieg examines how the medical pathologization of trans functions both as a discursive and literal denigration of trans subjectivities, but also as a political tool used by some trans people to access rights and (medical) services. She seeks to shift pathologization from the individual to society by framing society as limiting certain forms of gender expression. In this Krieg is inspired by the social model of disability to offer a broad challenge to understandings of trans pathology. While the main thrust of Krieg's argument is framed as a challenge to current modes of understanding, she also offers examples from recent policy changes that bring her argument to life.

Moving from the theoretical to the empirical, the second article de-

scribes the situation of Australian trans men, especially regarding how trans people are met within health care contexts (both within specialist trans health care and in primary health care situations). In "Mapping the Health Experiences of Australians Who Were Female Assigned at Birth But Who Now Identify With a Different Gender Identity", Damien W. Riggs and Clemence Due underline the importance of trans knowledge regarding the complexity and variance of trans experience, expression and needs, in order to ensure the effectiveness of treatment and to make sure that trans patients are listened to when dealing with health care providers.

The lack of knowledge amongst medical professionals and the effects of this upon trans persons are addressed in relation to a specific set of professionals in the next article. Trazcyk, Wurms and Ahonen's text focuses on interviews conducted with psychologists. In "Det är ju inget vi frågar efter som psykologer': Psykologers upplevelse av klienter med könsöverskridande beteende", the authors show how subjective assumptions about gender norms and ideals guide the professional reasoning of psychologists when working with questions of gender and gender identity, and how these also affect their approach towards patients. The authors suggest that increased trans cultural competence is necessary in order for a psychologist to be able to ask the patient relevant questions in relation to their gender identity, and suggest a parallel with the existing requirement for psychologists to have increased competence in ethnic and religious issues in order to better help patients from different ethnic and religious backgrounds.

Providing an interesting counterpoint to the voices of medical professionals in the previous article, the fourth article of this special issue takes its starting point from a recent radio programme about self-administration of hormones. Presenting a persuasive argument from an activist view point, Axel and Adrian Repka demonstrate how trans people are thought of as irresponsible, impatient, and sometimes even denied care because they are self-medicating in "The (Im)patients: An Analysis of How Stigma Leaks Through the Layers of the Trans Specific Health Care". This paper provides a pertinent example of gatekeep-

ing practices within health care, as well as highlighting a general lack of knowledge and understanding regarding trans experiences and situations. The authors argue for, and present, some suggestions for a more inclusive trans health care.

The fifth article of this special issue is by Lotta Kähkönen and offers a different perspective again on trans lives through a discussion of Jackie Kay's novel *Trumpet*. *Trumpet* is based on the life of Billy Tipton, a jazz musician who was female at birth, but lived his adult life as a man. "Reading the Potential of Jackie Kay's *Trumpet* for Transgender Ethics" highlights the disruptive potential of trans life stories which raise important questions about the "truth" of a person's identity. Examining the different ways in which trans life stories have been told, Kähkönen connects life writing and ethics in order to highlight "the creative capacity of art to transform materials from the past into resources of the future".

The special issue closes with Susan Stryker's inspiring keynote titled "Trans Health Is Queer (and Queer Health Isn't Normal)". In this paper Stryker highlights what she sees as one of the distinctive aspects of trans dialogues taking place in Sweden, and what could also be said to lie at the heart of developing good trans health (care): an interdisciplinary, multi-voiced dialogue between research, practice and policymaking. The main focus of the paper, however, lies in Stryker's marrying of "queer" and "health" which makes a powerful case for envisaging a kind of health care that cares for "life in all its urgent queer variety". Rooting this conceptual marriage in empirical data, she uses the example of an intake report from the Gender Management Services Clinic. Stryker highlights a small group who were deemed ineligible because they were "self-identified queer or questioning" and she uses this as a way in to exploring the powerful force of the normative, a power that "minimizes or eliminates some potentially viable expressions of life while nurturing and cultivating others".

#### Conclusion

As these summaries show, there are many intersections of trans and health under consideration here. There are strands of debate from activism, policy and literature, as well as from legal and medical contexts. The articles cover negotiations with health care for both transition and primary health care, and highlight the ways in which the health care system in general, and its practitioners in particular, may turn these negotiations into stigmatizing encounters. As one of the most heavily surveilled and disciplined arenas of contemporary life, the health care system wields almost unimaginable power over bodies, lives and futures. However, not only do the articles contained in this special issue highlight areas of tension and debate, they also identify ways in which the current health care systems could be improved. These include:

*Self-diagnosis*: In "The (Im)patients", Repka and Repka point to the importance of self-diagnosis as a way to avoid the gatekeeping aspect and effect of the gender identity disorder diagnosis, which today limits access to treatment based on gender binary norms.

*New models*: Krieg proposes a shift from the existing medical model of trans to a social model. This is inspired by the social model for understanding disability, which views the surroundings as that which limit a person's life. Applied to trans lives, this social model helps to show how social norms and expectations about gender limit the possibilities for expressing one's own gender, thereby actively working to depathologize trans lives.

Depathologization: Many of the articles argue for a depathologization of trans. Stryker, for example, draws on a feminist framework of reproductive rights as an example from another health care context where care is provided without pathologization. The Stop Transgender Pathologization (STP) movement mentioned in a number of the articles is also worth highlighting here:

We demand our right to freely decide whether if we want or not to modify our bodies. Our rights to be able to carry on with our decision, with no bureaucratic, political or economical impediments, nor any other type of medical coercion. (International Network for Trans Depathologization 2012)

Trans knowledge: The articles authored by Kähkönen, by Riggs and Due, and by Trazcyk, Wurm and Ahonen all stress the need for new or increased knowledge about trans lives. Greater understanding amongst both medical practitioners and the general public would address misconceptions about trans lives, offer a wider range of possible life narratives and potentially lead to better health care for trans persons. This is particularly important to ensure that the health care system is not guided by norms and ideals of normalcy, but rather by trans variance and perspective.

Finally, it is worth drawing attention to the theme of queerness which weaves its way more or less explicitly through many of the articles, and which highlights important questions about social norms and assumptions around authenticity and identity. A number of the papers address the reproduction of a gender binary by the health care system as part of the requirements to access transition. A number of the papers also strive towards a more nuanced understanding of trans inspired by queer perspectives. The multiplicity and variance epitomized by queer at its best can be seen to be fundamentally at odds with the neatly ordered world of health care, and therefore disruptive towards the received medical narrative surrounding transition and trans lives. As such, this special issue also offers examples of how ongoing debates about the relationship between trans and queer (Stryker 2004; 2006; 2008; Bettcher 2009; Raun 2012) are being played out in relation to critical perspectives on health.

The articles presented here highlight some specific examples and point to some important avenues for change. They also pose questions about contemporary understandings of "health" and "health care" as parts of a broader human rights framework. Who has the right to health care and what kind of health care does this assume? What would it mean if ascribing to contemporary norms of health is actually making some people "unhealthy"? What if the health care system is so out-of-sync with some bodies, that interacting with them can actually make a person less happy and healthy because they are forced into a model that is uncomfortable? What if every interaction with your health care provider reminds you that you do not fit the assumptions that they make

about your lifestyle, identity or sexual preferences? The articles included here do important work in showing the breadth, the scope and the life-limiting power of health care as it reaches into trans lives. We hope they will inspire you towards change as much as they inspire us.

We would like to give our warmest thanks to the authors and book reviewers who contributed to this special issue, to Susan Stryker for kindly agreeing to let us reprint her keynote, to Ulrika Dahl who calmly guided us through the process of putting the special issue together and to the anonymous reviewers for giving their time and energy to providing feedback on the articles.

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#### NOTES

- r. We use the term "trans" here as an umbrella term to mark the complexity of the identities and histories contained within the term, in order to include transsexual, transgender, intersexed and intergender as well as gender variant and third gender categories, and more. This is an open-ended term that can expand in response to new and alternative gender identity formulations. This is important in order to avoid unintended exclusions of persons, identities or expressions. The articles contained in this special issue use a variety of terms reflecting the authors' own linguistic choices.
- 2. One of these governmental investigations led to the Swedish gender reassignment law in 1972. Although progressive for its time, the law is now outdated as has been pointed out by two different governmental investigations (SOU 2007:16; Social-styrelsen 2010). The law has yet to be changed, although another law has made it possible to undergo gender reassignment without forced sterilisation (since July 2013), the result of massive trans political work in Sweden.