DELISTED

Alberta's arbitrary cutting and reinstating of gender reassignment surgery

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MASTERFILE

JESSICA WILLES'S DELICATE COMPLEXION reflects her pale-grey T-shirt, creating a translucent backdrop for her sparkly almond-shaped eyes. Wisps of her bob-length ash blond hair frame her face as she tilts her head, offers a slight smile and greets me with a feeble handshake. The soft-spoken 34-year-old Calgary woman takes a seat, crosses her legs and places her hands in her lap. Willes's movements appear innate, or, rather, characteristic of the mannerisms our society recognizes as feminine.

But there's an effort behind the motions, says Willes, who has spent the past few years perfecting the day-to-day gestures. "There's an emotional transition that goes along with gender [transition]," she says. "[You're] trying to learn as much as you can about the differences in gender: everything from speech, to etiquette, to discovering your fashion style… it takes time to figure out who you are."

The irony of that statement is that Willes knew who she was—a woman—from an early age. Her gender identity, however, was in conflict with her physiological sex. Willes is a trans-woman: a transgender person assigned as a male at birth but who has a female gender identity. She was 15 the first time she typed "gender transition" into a search engine. It was the mid-1990s and there were no support groups or informational pages on the Web about being transgender. Soon after, her father came across the browser history and things "exploded" at home. "It set me back a long time," says Willes. "We never talked about it again and it kind of disappeared."

But the reality of being a woman trapped in a man's body never did. Willes lived as a man until her mid-20s, until she could no longer ignore her overwhelming feelings and decided to begin her transition. After that came years of drawn-out and often painful therapies and procedures, including regular appointments with a psychologist, hormone therapy—high doses of testosterone blockers and estrogen—hair removal and surgeries. And then, four years ago, Willes was planning to complete her male-to-female transition by undergoing gender reassignment surgery (GRS), in her case vaginoplasty, a $20,000 procedure that creates female genitalia from penile tissue. The surgery, funded by the provincial government, was going to be the last stage of Willes's transition and the first step to moving on with her life in the body she was meant to have, she says.

But on April 7, 2009, much to Willes's and the rest of the Alberta transgender community's surprise, the government announced it was cutting GRS funding—effective immediately.

The following week, then-Minister of Health & Wellness Ron Liepert was challenged in the legislature by Edmonton-Centre MLA Laurie Blakeman (Lib) to explain the reasons for delisting GRS. "Why was there a complete lack of consultation with any medical professionals with expertise in this field?" she asked. Liepert replied that the delisting "was not based on medical decisions." It was a matter of making "very tough decisions" based on budget cuts, he said. The GRS delisting was to save around $700,000 of the province's $10.9-billion annual healthcare budget for that year and was part of a $215-million overall cut.

Even as he defended the cut to GRS, however, Liepert allowed that the delisting process might be flawed. Albertans, he said, should discuss whether the province needs "an expert panel to start to determine what is medically necessary, what is essential, what needs to be covered." To many Albertans, Liepert's comments came as a shock. How was it possible that a politician with no medical background could delist a medical procedure without consulting experts in the field—and without considering the delisting a "medical decision" in the first place?

Some people think Alberta's decision to delist GRS had a lot to do with transgender citizens' lack of rights.

THE PROCESS—OR LACK THEREOF—THROUGH which the provincial government makes decisions about listing medical services and procedures is indeed deeply flawed, says Dr. R. Michael Giuffre, president of the Alberta Medical Association (AMA). Too much power rests in the minister's hands: "It's very much… 'I'll make the decision, I'll watch the decision, and if [the pressure gets] too much, I'll reverse my decision.'"

Health ministers, he acknowledges, are often under pressure to make cuts to the healthcare budget while at the same time meeting public expectations. And healthcare needs are always changing. The minister must take into account an aging population, rising costs for pharmaceuticals, and new, advanced surgical and diagnostic procedures. This is why decisions about what medical procedures and services to cover need to be made through consultation with medical experts, says Giuffre. "From a physician's point of view, as soon as the Ministry of Health gets involved, it has the potential to interfere in healthcare… it threatens the physician–patient relationship," he says.

As gender identity disorder affects a small percentage of citizens, and GRS surgery is received by only around 16 Albertans per year, the procedure makes an easy target. "The most vulnerable [patients] tend to be the ones that get cherry-picked by a minister who says 'this will have the least political fallout, so let's delist this and save some money,'" says Guiffre.

Canadians receive coverage for "medically necessary" procedures and services under the Canada Health Act (CHA). In Alberta, the Alberta Health Care Insurance Plan provides additional benefits and services for "medically necessary" procedures that the CHA overlooks or ignores. Although the federal plan sets a template for what is "medically necessary" by the services and procedures it funds, it does not define the term, leaving plenty of room for interpretation by each provincial government. "It's purposely vague, set up on a broad definition, because what it boils down to is that medical necessity [varies by] patient," says Giuffre.

What is and is not covered varies from province to province because funding for provincially designated services and

procedures—which in most provinces includes GRS—is at the discretion, typically, of each province's minister of health. In Alberta—as in Manitoba, Saskatchewan and BC—although the Minister of Health can draw on medical reviews and literature and consult a committee that consists of physicians or experts (typically from the province's medical association), they aren't obliged to.

"What ends up happening is that delisting or relisting comes up when the government says we want good value, and we don't have enough dollars," says Giuffre. But he adds that cutting medically necessary procedures doesn't create value or save money. "Short-term squeezing of the system just increases pressure in other areas," he says. "And often those decisions end up being reversed because the public protests, and we end up right back where we started."

How can a minister with no medical background delist a surgery—and consider it a non-medical decision?

IT WAS BY READING HIS MORNING NEWSPAPER that Dr. Lorne Warneke learned GRS funding had been eliminated. Dr. Warneke is one of the few Alberta psychiatrists who see transgender patients and diagnose gender identity disorder (a requirement for GRS funding approval). When treatment was delisted, he was the sole psychiatrist in the province who had been requesting GRS funding on behalf of his patients, and he'd been doing so for more than a decade.

"If the Alberta government was going to do something that would have a major impact on the patient population, why wouldn't they contact the person who can make some comments on what that impact would be?" asks Dr. Warneke.

Despite popular misconception that GRS is a cosmetic surgery, it is a medically necessary procedure—often with life and death consequences, says Dr. Warneke. "People say it's a choice. Clearly, common sense would say Why would anybody choose to be transgender? It doesn't make any sense." Studies have proven that certain areas of the brain are sexually dimorphic, meaning that they are different in the brains of males and females. In trans-women, these areas are the same as in biological females, and the same is true with trans-men and biological men, says Dr. Warneke.

Due to societal ignorance, lack of acceptance and scarcity of resources, suicide attempt rates are some of the highest among the transgender community. According to a recent study out of Ontario by Trans Pulse (an NGO that researches access to health and social services), 43 per cent of trans-people have attempted suicide.

After delisting GRS in 2009, the Alberta government announced it would still fund the 26 people who were already approved and 20 more who had undergone irreversible physical changes with hormone therapy or initial surgeries. But even so, Dr. Warneke received a flood of frantic phone calls from people who no longer qualified for funding in 2009. "There was a lot of despair among older people but especially young people with their whole lives ahead of them, thinking What am I going to do?" he says, adding that when the government cut funding, it did not consider the irreversible psychological state of many transgender patients. Delisting "affected an entire group in our society that was a minority group and was already discriminated against."

Following the delisting announcement, two of the doctor's transgender patients were hospitalized for several weeks after suicide attempts—a great cost, both emotional and medical, that could have been prevented, Dr. Warneke says.

THE ALBERTA GOVERNMENT IN 1996 BEGAN funding final-stage gender reassignment surgery—vaginoplasty for trans-women and phalloplasty for trans-men—for patients who met a long list of clinical criteria based on the World Professional Association for Transgender Health Standards of Care. The criteria include a psychiatric diagnosis of gender identity disorder; one year of Real Life Experience, or living full-time in the desired gender; necessary hormone therapy; and preliminary surgeries (hysterectomies for trans-men, for example). Montreal's Centre métropolitain de chirurgie plastique is the only clinic in Canada where GRS is performed. The program does not fund what the government deems "cosmetic procedures," such as Adam's apple shaving, facial feminization and voice surgery for trans-women. Hormone therapy is also an out-of-pocket expense and drugs can cost upwards of $1,200 per year.

Physical gender transitions can take anywhere from two to 10 years, but emotional and psychological transitions often take much longer. For every transgender person, the journey is vastly different, and the idea of being complete in their transition varies widely. As the procedure is extraordinarily difficult, and patients are at risk for a number of side effects, many trans-men don't undergo phalloplasty, which costs approximately $60,000. Instead, they rely on the effects of testosterone therapy to achieve the primary and secondary male sex characteristics—larger external genitalia, muscle development, hair growth and lower voice pitch—they feel are enough for living as their true gender. Vaginoplasty, on the other hand, is a more common procedure, and the results of the surgery are often so successful that the constructed vagina is indistinguishable from a biological one.

For trans-women, even after estrogen therapy and testosterone blockers, characteristics that are already in place, such as bone structure, facial hair and voice pitch, do not change. (Estrogen therapy will result in breast growth and may soften facial hair to some degree.)

Because of costs associated with hair removal, and cosmetic procedures such as chondrolaryngoplasty (Adam's apple shaving), facial feminization to soften bone structure and voice surgery to achieve a more female-sounding voice, trans-women pay more out-of-pocket costs during transition than trans-men (hysterectomies and mastectomies for trans-men are covered under the Canada Health Act).

Willes saved up for years for the cosmetic procedures and was planning on getting them done first—to make her everyday life as a woman in society easier—before undergoing GRS. When GRS funding was delisted, she had to make a choice: spend her $20,000 on the facial and voice surgeries or spend it on GRS.

In the end, Willes went to a Boston clinic for the chondrolaryngoplasty and facial feminization and voice surgeries, because those changes would make her everyday life easier. "For me, having transitioned to the point where I can live in my gender role [day to day] has made a huge difference," says Willes, although she adds she will not feel complete in her transition until she has had GRS. Although Willes is lucky to have a supportive partner she can be intimate with, many trans-people don't have one, and will not consider having a partner prior to undergoing GRS. Sacrificing a healthy relationship and intimacy for the ability to go about everyday life without harassment and judgment, something most of us never think about, is not something Willes, or anybody, should have to do.

IN JUNE 2012 THE ALBERTA GOVERNMENT UNDER Premier Alison Redford reinstated GRS funding under the Alberta Health Care Insurance Plan for up to 25 people per year for an annual cost of about $1-million. "We're a new government now, and a new administration, and we view this issue very differently," says Health Minister Fred Horne. "This is an issue that affects a very small number of people in our province, but those that it affects, it affects profoundly." It was a welcome decision to members of the transgender community—and, like the delisting three years earlier, it came out of the blue.

This time the government did consult with medical professionals, including Dr. Warneke, before relisting the surgery. But as was the case with delisting GRS four years before, there was no formal process. And although the relisting is a victory for the transgender community, its members are aware that nothing stops the minister from cutting GRS funding again.

When I ask Horne about how easy it appears to delist and then relist a medical procedure if it's not under the Canada Health Act, he says that a case like the one in 2009 is a rare occurrence and more often the government adds rather than subtracts services. "Nobody takes any of these decisions lightly, because for everything you do fund, there are other needs that are not funded, because there are a finite amount of resources to work with," says Horne. "We don't see a lot of changes in the coverage." (According to the AMA, the last significant delist before GRS was in 1994 when the Alberta government cut funding for oculo-visual assessments, a.k.a. eye exams.)

Some members of the community think Alberta's decision to delist GRS had much to do with transgender Canadians' lack of rights. "Trans rights… are where queer rights were 40 years ago; we don't have employment protection or housing protection," says James Demers, a trans-man and Calgary activist who works closely with Alberta's transgender community and who adds that because there is no formal process or federal guidelines in place, delisting GRS could happen just as quickly again with a new government.

Transgender rights are changing, however. In March, Bill C-279 was approved by the House of Commons and at press time was awaiting Senate approval. The Bill seeks amendments to the Criminal Code and the Canadian Human Rights Act to mandate that gender identity and gender expression be taken into consideration at the time of sentencing under the former, and as prohibited grounds of discrimination under the latter. If it gains Senate approval and receives royal assent, the Bill will affect future decisions about services for transgender citizens.

A number of complaints were filed with the Alberta Human Rights and Citizenship commission after the province cut funding for gender reassignment surgery. This is something the province might have expected; a similar situation had occurred in Ontario a year earlier, when the delisting of GRS funding was ruled a human rights violation. (The Ontario government cut GRS funding in 1998 and faced a costly, decade-long court battle until the Ontario Human Rights Commission ruled the cut discriminatory on the basis of the province's Human Rights Code and forced the government to reinstate funding in 2008.) With Redford's decision to relist GRS, these complaints were withdrawn.

FROM THE AMA PERSPECTIVE, THE GRS case is a prime example of how decision-making about medical insurance needs to change. "We need an explicit, good process," says Giuffre. "We need to be able to scrutinize [decisions], see that they are transparent and see that they're fair. And the process needs to be based on clinical information that is reliable, that analyzes both the impact and the consequences of any type of delisting. It really has to be based on the input from healthcare providers on the frontline. And the input also has to involve patients."

Dr. Warneke would like to see the federal government create a set of guidelines for provinces that would offer consistency in what is funded, especially when it comes to GRS, and that would provide guidance to medical practitioners. He'd also like better care for transgender patients in Alberta. Apart from himself, few local medical professionals will treat transgender patients, he says, for reasons ranging from unfamiliarity with treatments to not being trans-friendly. On average, it takes eight months to see Dr. Warneke, who receives at least five referral requests per week. And only after the first appointment does the one-year Real Life Experience begin, even if the patient has already been living in the gender for some time.

As for Willes, she's just glad the surgery is funded again. She hopes to undergo GRS in the next couple of years and finally put it all behind her. "When you're struggling with the identity of being trans, there is so much self-loathing and so much self-hatred… You hate yourself so much and you give up and despair and want to end it all," she says. "To have the surgery would probably alleviate the last remaining self-loathing and self-hatred." ■

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