

The intersex gap in research and healthcare

Written by [Maria Cohut, Ph.D.](#) on July 1, 2020

Do you know what the “I” in LGBTQIA stands for? Medical News Today has



What does it mean to be intersex, and what are some of the challenges that intersex individuals face? We spoke to an intersex activist to find out.

Image credit: Bojan Cvetanović / Wikimedia Commons, 2019.

“Intersex” is a biological identity that gets little coverage and attention, not just in mass media, but also in terms of medical research and data collection.

At present, it remains unclear how many intersex people there are in the world.

That is, in part, because definitions of what it means to be intersex [vary](#). However, the term generally refers to people who are born with genitalia, and then develop other traits, that doctors cannot easily classify as pertaining to binary, or “male” or “female,” biological sex.

Many countries — and the United Kingdom is one such example — also fail to collect and store information about intersex newborns.

The U.K.'s Office for National Statistics, for instance, [note](#) that “[f]or births where the sex of a child is indeterminate or where there are intersex traits, the [official] advice [...] is that the registration [of the newborn] should be deferred until medical investigations have been completed.”

A word of introduction

Intersex individuals can also face a degree of unhelpful medical scrutiny. The American Psychological Association, for instance, [describe](#) “intersex” as “a variety of conditions,” and claim that the term “disorders of sex development (DSD)” might be “more accurate and less stigmatizing than the term intersex.”

Yet characterizing intersex as a type of disorder presupposes a clinical perspective with which not all intersex individuals agree. For example, the Intersex Society of North America — whose members included intersex activists and educators and which closed its doors in 2008 — [specify](#) that “[i]ntersex itself is not a disorder, rather a variation.”

They note that the word disorder “refers to the underlying cause, not intersexuality itself, and certainly not to the whole person,” though each intersex individual may choose to refer to themselves in a different way.

To get a better understanding of what it can mean to be intersex and what challenges intersex individuals may face in terms of accessing primary healthcare and mental health support, *MNT* has interviewed New York-based intersex educator [Aleksander Berezkin](#).

We have lightly edited the interview transcript for clarity.

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'Binary medical locks' with far-reaching consequences

Medical News Today: How would you explain "intersex" to someone who has never heard of the term?

Aleksander Berezkin: This is a good question. There are a lot of definitions. I chose the [one from U.N. Free & Equal](#). [N.B.: Free & Equal is a public information campaign from the U.N. Human Rights Office, for which Aleksander Berezkin volunteers.]

According to this definition: "Intersex is an umbrella term used to describe a wide range of natural bodily variations. Intersex people are born with sex characteristics (including genitals, gonads, and chromosome patterns) that do not fit typical binary notions of male or female bodies."

For example, I was born with an additional chromosome, XXY, and my body was slightly different before [I undertook] hormone therapy. I had big breasts (gynecomastia), wider hips, and narrow shoulders.

My body didn't develop muscles and [body] hair. However, intersex people are [all] so different that it is difficult to find [overarching] common characteristics for our bodies.

MNT: For decades, doctors have advised parents of newborn intersex babies to assign that baby one specific sex. What is the danger of these kinds of decisions?

Aleksander Berezkin: I can understand the logic of this "kind advice."

Doctors and parents think that they can protect intersex people from bullying, hiding us behind binary medical locks.

Unfortunately, these lies meant "to save" don't help intersex people with psychological and other consequences.

Some intersex people discover that they have a “wrong” gender identity when they become older. This can lead to intersex people no longer trusting others, experiencing deep depression, post-traumatic stress disorder [PTSD], and even suicidal thoughts.

There are a lot of intersex people who had [gender-assigning] surgery that harmed their bodies. They were forced to suffer physically for the sake of matching their bodies with the assigned sex, [and they experienced symptoms such as] loss of sensation, sexual dysfunction, or the limitation of body abilities.

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'It is challenging to find doctors who work with intersex adults'

MNT: What difficulties would you say intersex individuals encounter when they seek formal healthcare?

Aleksander Berezkin: First of all, we often have to live according to medical prescriptions. If the doctor decides to describe us as boys or girls, we sometimes don't have the right to control our bodies and gender identities as we want.

Secondly, most of us don't have access to medical records. Oftentimes, we can't say "no" to medical researchers who study us like mice for their scientific dissertations.

Intersex people should [also] be careful when talking with doctors about their intimacy and sexual life because some doctors can send us to psychiatric clinics if they decide we live out of the norms [they have established for] us. This happened to me in Russia.

[N.B.: Aleksander Berezkin is an asylee of Russian origin.]

There are a lot of doctors who want to work and "fix" intersex children, and it is challenging to find doctors who work with intersex adults, especially in a respectful, participatory manner.

Most insurances don't cover our hormone [therapy]. We [may] have to choose between a binary identity or physical disability [...] [or] to be ourselves and pay a high price for our freedom.

MNT: What about mental health? What might some of the mental health challenges be?

Aleksander Berezkin: Intersex people live in a situation of estrangement and nonacceptance. We continuously face fear and hate. We begin to be ashamed of ourselves.

We start denying ourselves, [thinking] that we cannot be like all people, with their unique characteristics. We are afraid to believe that we are human beings, too. We become used to societies' labels and stigmas.

We lose ourselves. It is difficult for us to open up and ask for help from other people. Thus, intersex people often live with the experience of deep trauma that connects with their bodies.

Can you imagine a person who lives [with] such violence and lies from the beginning?

When I think about intersex people, I often remember the Edvard Munch painting, [The Scream](#). Our scream is a cry of pain in the desert.

Unfortunately, there are not a lot of studies on how to provide mental support for intersex people. We are still one on one with this world.

'An intersex person may identify as female, male, both, or neither'

MNT: How would you say an intersex person might navigate the question of gender and gender roles?

Aleksander Berezkin: First, I would like to say that being intersex relates to biological sex characteristics, and it is distinct from a person's sexual orientation or gender identity.

An intersex person may be straight, gay, lesbian, bisexual, or asexual and may identify as female, male, both, or neither. Intersex people are very different.

We, like other people, want to have a right to bodily autonomy and health integrity, and we want to choose our gender roles ourselves.

I know some parents of intersex children in the United States and Germany who don't [try to] "fix" the bodies of their children, who give support, love, and warmth to them, who respect their rights to make their own choices about gender identity.

Intersex people need to have access to information regarding the spectrum of gender roles and how it could be connected with their bodies, and then [we, as] intersex people, can come up with our own solutions.

MNT: Finally, what advice would you give to *MNT* readers who would like to know more about intersex?

Aleksander Berezkin: If you would like to know more about intersex people and their problems, I would like to recommend the book "[Contesting Intersex: The Dubious Diagnosis](#)" by Georgiann Davis, a professor of sociology and an intersex person.