

INTERSEX HEALTH

“Intersex” refers to people whose bodies, reproductive systems, chromosomes and/or hormones are not easily characterized as male or female. This might include a woman with XY¹ chromosomes or a man with ovaries instead of testes. Intersex characteristics occur in one out of every 1500 births.⁽¹⁾ That means an intersex child is born every two days in Canada, and five intersex children are born each day in the US.

Within medical circles, the term “disorder of sex development” has replaced earlier terms such as sex reversal, hermaphrodite or pseudohermaphrodite.⁽²⁾ Intersex activist groups disagree about the appropriateness of this terminology.⁽³⁻⁴⁾ People living with this range of conditions generally refer to themselves as intersex.

ISSUES PARTICULAR TO INTERSEX PEOPLE

- Since the late 1950s, doctors routinely used surgery and hormone treatments to make intersex babies more closely resemble the sex assigned by the attending physicians.⁽⁵⁾ It is estimated that 30-80% of intersex children undergo more than one surgery and some have as many as five surgeries.⁽⁶⁾
- Intersex conditions were rarely disclosed, and many people were not aware that they were born intersex until they became teenagers. In some cases the physical changes they underwent at puberty did not match the sex in which they had been raised. Parents are now strongly encouraged to be open with intersex children about their medical history.^(1, 7-9)
- In the 1990s intersex adults began to speak out against surgery and hormone treatment on children, and the secrecy that surrounded it. They argued that such interventions caused emotional trauma and physical harm.⁽⁵⁾ A number of medical professionals soon joined them in opposing cosmetic genital surgeries for children.⁽¹⁰⁻¹⁶⁾
- Best practice guidelines now recommend against early genital surgeries. Parents are encouraged to wait until their child is old enough to be involved in any decision-making regarding changes to their body.^(1, 17)
- Most intersex people identify as either male or female, but not all intersex people identify with the sex they were assigned at birth. Estimates vary, but for some conditions, as many as 60% of intersex adults live as a gender other than the one in which they were raised.⁽¹⁸⁾

EXPERIENCES WITH HEALTH CARE PROVIDERS

- Intersex people suffer a lack of disclosure about their medical history from doctors and parents. Concealment practices prevent them from accessing peer support or making informed medical decisions.^(7, 17) In addition, the secrecy surrounding an intersex

¹ Women generally have XX sex chromosomes and men generally have XY

diagnosis can increase feelings of social stigma and damage a child's trust in their parents.^(7-8, 19)

- Intersex people have often been used for research without their informed consent, and photos of their bodies have been used without their knowledge. One researcher reports that former patients discovered naked photos of themselves as children in textbooks while researching their condition.⁽²⁰⁾
- Since English uses gendered pronouns, such as he and she, intersex people have sometimes been referred to with dehumanizing pronouns, such as "it".⁽²¹⁻²¹⁾ Most intersex people prefer to use masculine or feminine pronouns.
- As a result of treatment received as children, intersex people may be hesitant to seek out medical treatment for health problems.⁽¹⁹⁾

DIFFERENCES BETWEEN INTERSEX PEOPLE & LGBT PEOPLE

- The majority of intersex people identify as heterosexual.⁽¹⁸⁾ The percentage of intersex people who are gay, lesbian or bisexual is unclear, and methods of measuring orientation differ between studies. A small US survey done in 1968 found that 43.5% of intersex women reported same-sex fantasies.⁽²³⁾ A study done in 1987 found that only 2.5% of intersex people had engaged in sexual activity with a partner of the same sex.⁽²⁴⁾ A German study done in 1992 found that 20% of women with Congenital Adrenal Hyperplasia (CAH) wished for or had experienced same-sex relationships.⁽²⁵⁾ A Canadian study from 1996 found that 26.7% of intersex women measured as bisexual on the Kinsey Scale.⁽²⁶⁾
- Although intersex people may share issues in common with trans people, it is inaccurate to describe them as transsexual or transgendered. Trans people are not born with atypical sexual and reproductive systems and do not have the same history of surgical intervention during their childhood as intersex people.^(22, 27-28)

PHYSICAL & MENTAL HEALTH OF INTERSEX PEOPLE

- Some surgeries, such as the removal of testes or ovaries, have irreversible effects on the fertility of intersex people. Such procedures should be done only with the fully informed consent of the individual.⁽²⁴⁾
- Surgery on the genitals of intersex people often removes sexual nerve tissue, impairing their ability to enjoy a healthy sex life.^(17, 19) Traditionally, surgeons prioritized the fertility of intersex women and the appearance of their genitalia over their ability to experience sexual pleasure. Boys with small penises were often surgically altered to feminize them and then raised as girls, since it was assumed that men with small penises could not have satisfying sexual lives as adults.⁽¹⁹⁾
- Many intersex women are not sexually active and report difficulties with penetrative sex and/or a lack of sexual pleasure, which may be the result of surgical interventions when they were children. In a small UK study, only 22% of intersex women were sexually active, and half reported a lack of sexual pleasure as a result of surgery.⁽²⁹⁾ A London study found that a third of intersex women had never been sexually active, and had difficulty achieving orgasm.⁽³⁰⁾ Other studies in America and the UK suggest that 35-90% of intersex women may have difficulties with intercourse.^(24, 31)

- Intersex people with Frasier Syndrome (which affects skin development) may have a cancer risk as high as 60%.⁽³²⁾ Men with Klinefelter Syndrome (an extra X chromosome) may have a 40% chance of developing osteoporosis⁽³³⁾ and a risk of breast cancer fifty times that of other men.⁽³⁵⁾ People with CAH (which affects enzyme-production) may have low levels of cortisone, the hormone that helps us deal with stress, or may have problems maintaining their salt levels.⁽³⁴⁾ Other intersex conditions put people at risk for scoliosis, diabetes, lupus, or for kidney, cardiovascular, or thyroid problems.⁽³⁶⁾
- Research is unclear whether intersex people are at increased mental health risk. Some studies have found that intersex women are psychologically and socially well adjusted,⁽²⁹⁾ while other research suggests that intersex people may be at high risk for mental illness.⁽³⁷⁾

GAPS IN THE RESEARCH

- Since intersex people are a minority, and due to the history of secrecy surrounding intersex diagnoses, statistically representative data on intersex people is lacking.
- Research is needed on the lived experience of intersex people who have not undergone multiple surgeries in childhood to better assess the physical and social effect of the conditions themselves, apart from problems related to medical interventions.
- There is a lack of long-term longitudinal studies on the psychological and physical impact of various treatment models on intersex people. As a result, many doctors, parents and individuals make decisions about medical care that are not evidence-based.
- As many as 40 conditions are contained under the umbrella term “intersex”.⁽³⁶⁾ Additional research is needed on the health risks associated with each variation.

IMPLICATIONS FOR HEALTH CARE PROVIDERS

- Since intersex conditions are common, it is important for clinicians to ask clients about their sex and gender identities rather than making assumptions based on appearance. Although some intersex people do not identify as male or female, most do. If you are unsure about a client’s preferred gender pronouns, ask politely.
- Intersex people and their families need access to clear, accurate, and reliable information so they can make informed decisions. They may also need supportive counselling and peer support.
- Intersex people whose physical development at puberty conflicts with their gender identity (sense as themselves as male or female) should have access to hormonal treatment if they desire to suppress unwanted effects such as periods or beard growth.
- Intersex people may experience unique medical or psychological barriers to developing a healthy sex life. In addition, some intersex people may require fertility treatments to become parents or need supportive medical assistance during pregnancy and birth.
- Intersex people with a high risk for cancer or other health problems may need more frequent checkups. Models of care that affirm the autonomy and dignity of the client can increase the likelihood that intersex people receive the preventative medical care they need.
- Intersex people often have trouble accessing their medical records. Ensuring access may require changes to the Canada Health Act, which currently allows the head of

medical institutions to withhold a patient's medical records if they feel it is in the client's best interest. In practice, this provision has been used paternalistically.

- Clinicians who perform intimate examinations can help their clients feel more comfortable by offering a variety of privacy options. Clients may prefer to wear their own clothes in place of a paper garment, or have a friend hold their hand during a physical exam. Discussing their professional life during a pelvic exam may help dispel feelings of powerlessness and prevent intersex clients from re-experiencing previous medical traumas.
- Some intersex conditions may not be discovered until well into adulthood. This may have a significant psychological impact when discovered.
- Some intersex people may not be comfortable with the term 'ambiguous genitalia'. It is advisable to check with the client as to what terminology they prefer.

Resources

More information can be found on the following websites:

Accord Alliance: www.accordalliance.org

Intersex Initiative: www.ipdx.org

Intersex Society of North America <http://www.isna.org/>

[Note this organization is no longer active, but their website is archived online and contains valuable resources].

References

- (1) Consortium on Disorders of Sex Development. Handbook for Parents. 2006.
- (2) Consortium on Disorders of Sex Development. Clinical Guidelines for the Management of Disorders of Sex Development in Childhood. 2006.
- (3) Koyama E. Frequently Asked Questions about the "DSD" Controversy. 2008; Available at: <http://www.intersexinitiative.org/articles/dsdfaq.html>.
- (4) Intersex Society of North America. Why is ISNA using "DSD"? 2006; Available at: <http://www.isna.org/node/1066>
- (5) Gay and Lesbian Medical Association and LGBT health experts. Healthy People 2010 Companion Document for Lesbian, Gay, Bisexual, and Transgender (LGBT) Health. 2010.
- (6) Fausto-Sterling A. Sexing the body: Gender politics and the construction of sexuality. New York: Basic Books; 2000.
- (7) Intersex Society of North America. What does ISNA recommend for children with intersex? 2008; Available at: <http://www.isna.org/faq/patient-centered>.
- (8) Lee PA, Houk CP, Ahmed SF, Hughes IA. Consensus statement on management of intersex disorders. Pediatrics 2006; 118(2):488-500.
- (9) OII: International Intersex Organization. Handbook For Parents. 2008.
- (10) Kessler S. Lessons from the Intersexed. New Brunswick, NJ: Rutgers University Press; 1998.
- (11) Dreger A. Intersex in the Age of Ethics. Hagerstown, MD: University Publishing Group; 1999.
- (12) Diamond M, Sigmundson HK. Sex reassignment of birth: A long term review and clinical implications. Archives of Pediatric and Adolescent Medicine 1997; 150:298-304.
- (13) Foley S, Morley GW. Care and counseling of the patient with vaginal agenesis. The Female Patient 1992; 17:73-80.
- (14) Schober J. Feminizing genitoplasty for intersex. In: Stringer MDO, K.T., Mouriquand PDE, editors. Pediatric Surgery and Urology: Long Term Outcomes London: W.B. Saunders; 1998. p. 549-558.
- (15) Schober JM. Early feminizing genitoplasty or watchful waiting. Journal of Pediatric and Adolescent Gynecology 1998; 11(3):154-156.
- (16) Phornphutkul C, Fausto-Sterling C, and Gruppuso PA. Gender self-reassignment in an XY adolescent female born with ambiguous genitalia. Pediatrics 2000; 106:135-137.
- (17) Creighton S, Anderson EG, Minto C. Managing intersex: Most vaginal surgery in childhood should be deferred. British Medical Journal 2001; 323 (7324):1264-1265.
- (18) Migeon CJ, Wisniewski AB, Gearhart JP, Meyer-Bahlburg HFL, Rock JA, Brown TR, et al. Ambiguous genitalia with perineoscrotal hypospadias in 46,XY individuals: long-term medical, surgical, and psychosexual outcome. Pediatrics 2002; 110(3):e31.
- (19) Intersex Society of North America. What's wrong with the way intersex has traditionally been treated? 2008; Available at:

- <http://www.isna.org/faq/concealment>.
- (20) Creighton S, Alderson J, Brown S, Minto CL. Medical photography: Ethics, consent, and the intersex patient. *British Journal of Urology* 2002; 89 (1):67-71.
- (21) Koyama E. What Is Wrong With "Male, Female, Intersex". 2008; Available at: <http://www.ipdx.org/articles/letter-outsidein.html>.
- (22) Intersex Initiative. Intersex FAQ (Frequently Asked Questions). 2008; Available at: <http://www.intersexinitiative.org/articles/intersex-faq.html>.
- (23) Ehrhardt AA, Evers K, Money J. Influence of androgen patients with congenital adrenocortical virilism and some aspects of sexually dimorphic behavior in women with late-treated adrenogenital syndrome. *Johns Hopkins Medical Journal* 1968; 123:115-122.
- (24) Mulaik RM, Migeon CJ, Rock JA. Fertility rates in female patients with congenital adrenal hyperplasia due to 21hydroxylase deficiency. *New England Journal of Medicine*, 1987; 316:178-182.
- (25) Dittmann RW, Kappes ME, Kappes MH. Sexual behavior in adolescent and adult females with congenital adrenal hyperplasia. *Psychoneuroendocrinology* 1992; 17 (2-3):153-70.
- (26) Zucker KJ, Bradley SJ, Oliver G, Blake J, Fleming S, Hood J. Psychosexual Development of Women with Congenital Adrenal Hyperplasia. *Hormones and Behavior* 1996; 30:300-318.
- (27) Intersex Society of North America. What's the difference between being transgender or transsexual and having an intersex condition? 2008; Available at: <http://www.isna.org/faq/transgender>.
- (28) Koyama E. Adding the "I": Does Intersex Belong in the LGBT Movement? 2008; Available at: <http://www.intersexinitiative.org/articles/lgbti.html>.
- (29) Morgan JF, Murphy H, Lacey JH, Conway G. Long term psychological outcome for women with congenital adrenal hyperplasia: cross sectional survey. *British medical Journal* 2005; 330:340-341.
- (30) Minto C, Creighton S, Woodhouse C. Long Term Sexual Function in Intersex Conditions with Ambiguous Genitalia. *Journal of Health Psychology* 2001; 1 (4):479-492.
- (31) Minto C, Creighton S. Sexual Function in Adult Women with Complete Androgen Insensitivity Syndrome. *Fertility & Sterility* 2003; 80 (1):157-164.
- (32) Cools M, Drop SLS, Wolfenbuttel KP, Oosterhuis JW, Looijenga LHJ. Germ Cell Tumors in the Intersex Gonad: Old Paths, New Directions. *Moving Frontiers. Endocrine Reviews* 2006; 27 (5):468-484.
- (33) Ferlin A, Schipilliti M, Di Mambro A, Vinanzi C, Foresta C. Osteoporosis in Klinefelter's syndrome. *Molecular Human Reproduction* 2010; 16 (6):402-410.
- (34) Intersex Society of North America. Congenital Adrenal Hyperplasia (CAH) medical risks. 2008; Available at: http://www.isna.org/faq/medical_risks/cah.
- (35) Hultborn, R, Hanson, C, Kopf, I, Verbiene, I, Warnhammar, E, Weimarck, A. Prevalence of Klinefelter syndrome in male breast cancer patients. *Anticancer Research* 1997; 17 (6D): 4293-4297.
- (36) TransFaith InterSections. Types of Intersex Conditions. n.d.; Available at: <http://www.transfaithonline.org/intersections/intersex/types/>.
- (37) Slijper FME, Drop SL, Molenaar JC, de Muinck Keizer-Schrama MD. Long term psychological evaluation of intersex children. *Archives of Sexual Behavior* 1998; 27:125-145.

ACKNOWLEDGEMENTS

This fact sheet has been written with the thoughtful assistance of Dr. Morgan Holmes, Associate Professor of Sociology and of the MA program in Cultural Analysis and Social Theory at Wilfrid Laurier University, and Rodney Hunt, PhD Candidate, Department of Sociology at Simon Fraser University.

Feedback on this document is welcome. Comments and questions can be addressed to Lorelee Gillis: lgillis@RainbowHealthOntario.ca

Last updated: August 2011