

UNISON working for intersex equality

UNISON is one of the UK's largest trade unions, with more than 1.3 million members. We represent all staff who provide public services, whether they work in the public, private or voluntary sector. UNISON has a long and proud history of working for equality.

Introduction

There is growing awareness of the need to address workplace issues for people born with intersex bodies / non-normative sex characteristics. However, there is very little comprehensive research in the UK. There is a lack of understanding of intersex issues and lack of voice and visibility of those born with intersex bodies / non-normative sex characteristics. This factsheet is based on existing research and input from those affected and their allies.

Intersex is not the same as gender identity or sexual orientation. People born with intersex bodies have the same diversity in sexual orientation and gender identity as anyone else. LGBT activists and intersex activists may work together, but it's important to be clear about the difference and play our part in dispelling misunderstanding and confusion.

This factsheet aims to:

- promote understanding of issues experienced by those born with intersex bodies / non-normative sex characteristics
- equip UNISON reps to support members born with intersex bodies / non-normative sex characteristics
- raise awareness of the human rights of people born with intersex / non-normative sex characteristics, especially in relation to their treatment within the medical system.

This will help build inclusive workplaces that challenge discrimination and prejudice. It will give these workers equal access to support at work from employers and branches.

It is a working document that will evolve as our understanding and practice develops.

Terminology

Intersex is an umbrella term for people born with variations of sex characteristics which do not always fit society's perception of male or female bodies.

Non-normative sex characteristics is also used as an inclusive term, synonymous with intersex. Some people find it less stigmatising and easier to use or identify with than intersex.

Other terminology

DSDs: This was introduced as a medical term in 2006 by the medical profession meaning 'disorders of sex development' as many of those affected found the label intersex stigmatising.

However, it too is a very unpopular term amongst some intersex activists. It suggests something is wrong with the body that needs to be 'fixed'. This feeds into the narrative of the 'need' for surgeries which in most cases are medically unnecessary.

Some groups are now reclaiming DSDs as 'differences of sex development'. It is also widely used in academic research and by the growing number of psychologists employed to work in this area.

Hermaphrodite: this term is generally considered offensive and should not be used to describe people born with intersex bodies / non-normative sex characteristics.

Conditions leading to people being born with intersex bodies

Over 30 conditions lead to variations of non-normative sex characteristics. Some people refer to their condition, rather than being intersex. These conditions include:

- Androgen Insensitivity Syndrome (AIS)
- Congenital Adrenal Hyperplasia (CAH)
- Hypospadias
- Klinefelter syndrome/ 47xxy
- Turner Syndrome
- Rokitansky syndrome
- Ovo-testicular 'syndrome'
- 5-Alpha Reductase deficiency
- Swyer Syndrome
- Partial Gonadal Dysgenesis

It is estimated that as many as 80% of intersex variations have no formal diagnosis at all. Differences in sex characteristics can be found at birth, identified in childhood, adolescence or as adults, and some never become known.

The term intersex is used to find a platform to discuss common experiences while addressing the considerable differences in the impact of conditions on individuals.

However, it is important for trade union activists to be aware and respect that people affected have different views on terminology and how they identify themselves personally (NISR, 2015 p.24-25) when working with individuals and organising activities to promote understanding.

Challenges people born with intersex bodies/non-normative sex characteristics face

“When we talk about intersex, we are talking about a lifelong history of shame, secrecy and isolation that are imposed on children who were born with slightly different bodies” (Emi Koyama, Intersex Initiative)

- Lack of awareness and understanding across all sectors of society, including the workplace
- People frequently experience bullying over their perceived difference
- Their lives and experiences are largely rendered invisible in the education system
- At work, they fear discrimination or becoming objects of curiosity
- Fertility issues
- Lifelong medical treatment

Workplace issues

Conditions under the intersex umbrella vary significantly so there is a wide range of workplace issues, many very specific. People often have a deep sense of shame and may have been told to be silent about their condition. They may not have the words needed to get help. Where UNISON reps already have a basic understanding, this can make a huge difference.

Workers with intersex family members may also experience workplace issues.

Key steps for UNISON are to:

- Support members experiencing discrimination at work due to being intersex
- Promote understanding of issues, including the impact on individuals, families and friends when a child is born with intersex characteristics or discovers their difference later in life

- Recognise that individuals and families may find it hard to discuss and may need support raising workplace issues
- Raise awareness of intersex conditions with occupational health departments
- Promote clear definitions and challenge oppressive language
- Challenge terminology which adds to negative stereotypes and stigma, for example 'disease, disorder, abnormal'
- Support people's right to confidentiality. They may fear being bullied, treated differently or having to 'educate' others if colleagues find out.
- Don't expect people to be open or willing to discuss their lives and experiences
- Recognise some conditions fall within the protected characteristic of disability under the Equality Act 2010
- Support members seeking reasonable adjustments, making sure employers tailor the approach to the needs of that person, rather than make assumptions about the needs of intersex people.

Support from UNISON

UNISON can make a real difference to the working lives of people born with intersex bodies / non-normative sex characteristics.

UNISON will:

- Promote understanding of what intersex means and debunk misunderstanding and myths
- Raise awareness of human rights, especially in relation to unnecessary and non-consensual surgeries
- Develop our network to consult people born under the intersex umbrella so their voices are central to this work
- Campaign for an additional protected characteristic of 'sex characteristics' in the Equality Act 2010, covering being born with intersex bodies / non-normative sex characteristics.

The social model of disability is important in this context. Disability is caused by the way society is organised, rather than a person's impairment or difference. UNISON works to remove barriers that restrict choices for disabled people. We are committed to removing these barriers in how we think, talk, act and organise workplaces, union activities and society. We take this understanding into our negotiations with employers and representation of members.

Further information

Support groups / intersex organisations

- AIS support group (UK) www.aissg.org.uk
- Living with CAH (UK) www.livingwithcah.com
- Klinefelter syndrome association UK www.ksa-uk.net
- Turner Syndrome Support Society (UK) www.tss.org.uk
- Organisation Intersex International <https://oii.org.au/>
- Intersex UK www.intersexuk.org
- InterACT (youth action organization) interactyouth.org

Further reading

- [We Are Real: The Growing Movement Advancing the Human Rights of Intersex People](#) (Astrea Foundation, 2016)
- Living with intersex/DSD: An exploratory study of the social situation of persons with intersex/DSD (Netherlands institute for social research, 2015)
- <http://oii-europe.org/wp-content/uploads/2016/02/How-to-be-a-great-intersex-ally-A-toolkit-for-NGOs-and-decision-makers-December-2015.pdf>
- <https://www.tuc.org.uk/equality.../disability>

Books

- Annabel (Kathleen Winter, 2011)
- Fixing sex: Intersex, medical authority and lived experience (Katrina Karkazis)
- Golden boy: a novel (Abigail Tarttelin)
- She's a boy (Joe Holliday, 2015)

Films / Social Media

- Intersexion (2012)
- Interface project
- Buzz feed

How you can get involved

We are developing our work on intersex equality. If you have an interest in being part of this, please get in touch with Carola Towle, UNISON membership participation unit – contact details below.

Please raise the points set out in this factsheet in your branch. All branches should have an

equality co-ordinator and many have workplace equality reps.

To find out more

- Visit our webpages www.unison.org.uk/equality
- Ring UNISON *direct* 0800 0857 857 for details or your branch equality reps or to speak to Carola Towle
- Write to Carola Towle, national officer – membership participation unit, UNISON Centre, 130 Euston Road, London, NW1 2AY
- Or email equality@unison.co.uk

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