Promoting Intersex Rights in Italy.

A joint consensus statement shared by those concerned with the rights of people with Variations of Sex Characteristics (VSC) in Italy.

Declaration of the Italian VSC National Forum

Scope of this document

This document wants to provide a clear, collective stance on the rights of people with Variations of Sex Characteristics (VSC), including their priorities and claims, shared by the Italian realities that address them. The document includes a list of recommendations that hope to inform future medical guidelines that are respectful of the stakeholders' human rights.

This document is divided in six sections:

1. Introduction
2. Rights
3. Health and Wellbeing
4. Policies, Inclusion and Support
5. Guidelines
6. Terms and Definitions

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When quoting this document, please use the following:

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This document is available on the websites of the communities that contributed to its writing. On Intersexesiste.com website you will find a list of the people or allied realities that endorse it.

1. INTRODUCTION

Variations of Sex Characteristics (VSC) is an umbrella term referring to people with innate variations of their sex characteristics (including reproductive organs, genitalia, hormone levels, and/or sex-specific chromosomes) which do not fit the typical binary medical and social notions of male or female bodies.

People with VSC have always existed in every culture and society. Their existence is completely natural, and is worth being celebrated. In Italy, the widespread lack of awareness around the issues faced by people with VSC often forces them to undergo unnecessary and harmful 'normalizing' procedures, and to face discrimination and prejudices on a social level.

Insights provided by stakeholders and scientific research alike highlight how such discrimination, prejudice, and human rights violations persist even today, despite thirty years of public outcry condemning such detrimental medical procedures and their connected health risks for people with VSC.

As of today, the few large-scale studies completed in the United States (Rosenwohl-Mack et al. 2020), Europe (Nordenström et al. 2018), and Australia (Jones et al. 2016) show that medical procedures performed during infancy, as well as the associated social stigma, often lead to negative outcomes in terms of health and wellness for people with VSC.

Currently, the treatment of people born with VSC is left to the free initiative of the individual hospital or medical specialist, which often adopts an unjustifiably interventionist attitude informed by outdated medical protocols based on psycho-social justifications, unsupported by research and criticized by people with VSC themselves.

This document intends to clarify the requests of the Italian community concerned with promoting the rights of people with VSC, also known as 'Forum Nazionale VCS Italiano' (the Italian VSC National Forum), and to provide some guidelines on how to achieve the change that the Forum hopes will be realized.

In the context of this document, the terminology of preference will be 'Variations of Sex Characteristics' and the related acronym 'VSC', as it is less stigmatizing and preferred by those directly affected.

2. RIGHTS

We recognize Italy's international obligations, which has signed the Convention Against Torture (CAT), the Convention on the Rights of the Child (CRC), the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), and the Convention on the Rights of Persons with Disabilities (CRPD).

We would like to recall that on more than 50 different occasions UN bodies have called on governments, policymakers, and relevant parties to put an end to the human right violations suffered by people with VSC. They have been invited to adopt the necessary measures to respect for self-determination as well as the mental and physical integrity of people with VSC. Specifically, Italy has been condemned by UN bodies for its failure to protect the rights of intersex people:

- In 2016, by the UN Committee on the Rights of Persons with Disabilities (CRPD/C/ITA/O/01).
- In 2019, by the UN Committee on the Rights of the Child, under 'harmful practices' (CRC/C/ITA/CO/5-6).

In particular, in Paragraph 23, the CRC invited Italy to:

a) Develop and implement a child rights-based health-care protocol for intersex children, setting the procedures and steps to be followed by health teams, ensuring that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support;
b) Educate and train medical and psychological professionals on the range of sexual, and related biological and physical, diversity and on the consequences of unnecessary surgical and other medical interventions for intersex children.

Among the international resolutions condemning the performance of procedures on people with VSC without their direct consent, we note the following:

- World Health Organization (WHO) 2014, Eliminating forced, coercive and otherwise involuntary sterilization, An inter-agency statement.
- EU Agency for Fundamental Rights (FRA) 2015, The Fundamental Rights Situation of Intersex People.
- The Yogyakarta Principles plus 10 2017, which defines sex characteristics as protected grounds.

- Council of Europe (COE) 2017, Promoting the Human Rights of and Eliminating Discrimination against Intersex People, Resolution No 2191.
- European Parliament (EP) 2019, The rights of intersex people, Resolution 2018/2878(RSP).
- European Commission (EC) 2021, EU Strategy on the Rights of the Child.

We would also like to point out the following EU states that have adopted specific regulations to protect the rights of intersex people and prohibit the performance of deferrable procedures on people with VSC, in particular when they cannot express their consent.

- Malta, 2015, Gender Identity, Gender Expression and Sex Characteristics Act (GIGESC). It recognizes sex characteristics as protected attributes and acknowledges the right of minors with VSC to bodily autonomy and integrity.
- Germany, 2021, Gesetz zum Schutz von Kindern mit Varianten der Geschlechtsentwicklung. It prohibits the performance of any medical procedure aimed at assigning a specific gender to a minor who has not provided their express consent.
- Greece, 2022, Law 4958/2022 (Art 17-20). It prohibits IGMs (Intersex Genital Mutilations) and other harmful medical procedures without the direct consent of the person involved, even when they are still minors.

We endorse the declarations of the human rights associations for people with VSC, including:

- The Malta Declaration 2013
- The Riga Statement 2014
- The Vienna Statement 2017
- The Darlington Statement 2017
- The African Intersex Public Statement 2017, 2019, and 2023
- The Asian Intersex Movement Public Statement 2018
- The San José de Costa Rica Statement 2018

We ask for

A. the immediate cessation and the introduction of the prohibition of all deferrable surgical procedures and hormonal treatments that irreversibly change a person’s sex characteristics, in particular when there are no concrete health risks for them, and without their personal freely given fully-informed consent, even when they are minors. In this regard, the relevant authorities must promote the necessary laws and regulations for the protection of the right to bodily self-determination and integrity of people with VSC;

B. minors with VSC to be fully informed and involved in all medical decisions that directly affect them, as stipulated in the Convention on the Rights of the Child. That children and families are presented with a full overview of all health outcomes, as well as of other viable solutions, in a simple child-friendly manner, in an easily understandable language;

C. an efficient legal protection against discrimination and harmful practices based on sex characteristics to be put in place. In order to achieve this, we suggest that ‘sex characteristics’ are specified as a reason for discrimination (protected ground) in the legal text itself;

D. people born with VSC to be guaranteed low-threshold modification of their registered sex, ensuring full autonomy. Our hope is that legal sex attribution on birth certificates and identity documents will be overturned in general. However, please note that the request for the bodily autonomy and integrity of minors with VSC does not constitute a request for the addition of a third legal gender/sex. Attempts to group all people with VSC under a single ‘third gender/sex’ category does not respect the diversity of bodies and experience, as well as the right to self-determination. Where it is not possible to overturn legal sex attribution, people who are able to provide their consent must be given the chance to choose between a variety of different legal categories that reflect their identity, beyond female (F) or male (M) binarism;

E. real participation and inclusive consultation of people born with VSC and VSC Organisations (defined as organisations led by people with VSC that advocate for and protect the human rights of people with VSC) in all issues and policies that affect them;

F. the establishment of a governmental commission of inquiry regarding the harm caused by normalising medical procedures. The establishment of possible compensation formulas for people who have suffered genital mutilation or other irreversible damage, to overcome the current problem of the statute of limitations;

G. access to and sharing copies of complete and accurate clinical records in a timely manner;

H. the non-consensual sterilisation of people with VSC to be abolished;

I. the abolishment of pre-natal treatments and selective abortions of fetuses with VSC;

J. the depathologisation of variations of sex characteristics in medical guidelines, protocols, and classifications;

K. the human rights and citizenship rights of people with VSC to be guaranteed;

3. HEALTH AND WELLBEING

There is a need to abandon the current medical model, focused on forced social ‘normalisation’ through the bodily modification of minors with VSC in favour of an approach that prioritises their welfare and needs throughout their life, fully respecting their human rights. Unnecessary procedures during infancy can result in serious, irreversible negative outcomes, that can impact a person’s physical and mental wellbeing throughout their life. Currently, there is a lack of support for families and those directly affected. Data and research focusing on the long-term health and wellbeing of people with VSC is lacking, meaning that more often than not the treatments offered (e.g., hormonal therapies) are based on the needs of other segments of the population. Health professionals do not receive training about VSC and tend to confuse them with sexuality and gender identity issues, which can cause difficulties for stakeholders to access healthcare. Given the amount of trauma that people with VSC have had to withstand during infancy and puberty, they can also be unwilling to pursue medical treatment once they reach adulthood.

We ask for

A. a non-interventionist paediatric protocol that supports families and ensures the physical and mental wellbeing of future adults with VSC;
B. psychosocial support to be the primary paediatric intervention offered to families.
C. families to be referred to peer-support organizations that acknowledge and protect the rights of people with VSC as early as possible;
D. diagnostic exams to be performed with full respect of the person during medical visits, and that they are exclusively limited to a person’s health needs;
E. the prohibition of photographs of naked bodies and genitals; exams performed in the presence of several health professionals at the same time; and invasive examinations (e.g., taking measurements of genitals, palpation, etc.) performed on minors, in particular if these examinations are performed in the name of ‘research’. People who are not sexually active not to be subject to penetrative medical examinations similar to intercourse, and in any case not without their explicit and informed consent;
F. communication with the child/children to be as complete and non-stigmatizing as possible during each meeting in which their variation is discussed, using accessible and age-appropriate language;
G. for parents to be provided with clear information that allows them to make informed decisions, including information regarding the risks of any deferrable procedures aimed at normalizing bodies based on cosmetic requirements related to the binary society;

H. people to be granted access to their complete clinical records and history;

I. appropriate psychological support for people with VSC who request it, particularly if they had to undergo traumatic and/or unnecessary medical procedures;

J. the establishment of regional health and legal support centres for individuals and families, in collaboration with VSC Organisations, as well as the implementation of a network of appropriately trained psychologists;

K. training activities for all health professionals nationwide, with special reference to paediatricians, neonatologists, psychologists, obstetricians, endocrinologists, and GPs.

L. The funding of peer-support groups and VSC Organisations;

M. the funding of research projects focused on the health and wellbeing of teenagers and adults with VSC - developed in collaboration with those directly affected and VSC Organisations.

N. the funding of research on hormonal therapies for different variations throughout the life course;

O. the funding of research on how to safeguard the reproductive capacity of people with VSC;

P. transparent, accurate, and updated data collection regarding the health of people with VSC and the medical procedures they undergo. That this data is easily accessible and disaggregated by sex and gender;

Q. general healthcare to be provided to people with VSC free of any prejudices and unwanted attention, in particular when the VSC is not related to the medical issue. Ignorance and associated stigma on the part of health professionals can be a barrier to proper healthcare;

R. the funding of psychological, health and social research involving teenagers, adults and seniors with VSC.

4. POLICIES, INCLUSION AND SUPPORT

Attitudes toward people with VSC are influenced by the importance that the social context in which they live places on gender stereotypes, gender discrimination, and social and cultural norms that divide bodies and roles into male and female. The maintenance of a binary model that classifies biological sex and gender into two distinct, mutually-exclusive categories, leads to the pathologisation, discrimination, marginalisation, violence, and erasure of all people whose biological sex, gender identity and expression do not meet the social expectations of this binary logic.

Accordingly, the contributors to this document highlight the need to create a more inclusive, aware, and informed society, that disrupts the socio-cultural mechanisms upon which the discrimination, violence and pathologisation faced by people with VSC during their interaction with medical, religious, work, administrative, legal and social realities is based. In this sense, we acknowledge the fundamental importance of sharing positive stories and positive media coverage of people with VSC.

We ask for

A. Italian health professionals and paediatricians to be trained on the topic by VSC Organisations, with training materials developed along with VSC Organizations, including testimonies of those directly affected;
B. school teachers and auxiliary staff to be properly informed and trained to work with people with VSC by VSC Organisations, in order to prevent discrimination and bullying episodes as well as promote inclusion and respect for differences;
C. the inclusion of accurate and affirmative material on bodily diversity (including VSC) in school curricula regarding health and sex education, developed together with VSC Organisations to fit different age ranges and cognitive abilities;
D. civil service employees, public service representatives, law enforcement and armed forces to be properly informed and trained on the topic with the involvement of VSC Organisations;
E. professional bodies, entities or associations interested in receiving a proper training on VSC use materials developed by or in conjunction with VSC Organisations;
F. the impact of stigma, trauma and unwanted medical interventions be acknowledged with regards to access to education and employment. For the direct repercussions on mental and physical health as well as financial and social conditions be recognised;

G. cultural and sport associations and organisations to promote and encourage the inclusion of people with VSC, creating environments free from prejudice and abuse;

H. law enforcement agencies and armed forces of any kind to accept people with VSC in their ranks;

I. employers, governments, institutions, and trade unions to develop positive policies and practices aimed at supporting employees with VSC;

J. the media to cooperate with VSC Organisations to improve the understanding of human rights issues and concerns;

K. specific rules to be added within the journalists' code of conduct that protect people with VSC, emphasizing the need to respect the privacy and safety of the people involved;

L. VSC Organisations to receive the resources necessary to protect and safeguard the human rights of people with VSC both within and outside of hospitals and clinics;

M. the National Register of Rare Diseases to be updated, in particular regarding exemptions from medical fees and 'disease' terminology. For the use of revised, less offensive language when referring to people with VSC, ensuring that all possible corrections are forwarded to all medical facilities and realities across the Italian territories;

N. people with VSC to be protected from discrimination based on sex characteristics also in migratory contexts, in addition to protection from cultural and racial discrimination;

O. the addition of the letter 'I' to the LGBT+ acronym to reflect full support for the rights and demands of people with VSC, and for stakeholders and VSC Organisations to be purposefully included.

5. GUIDELINES

In the absence of national guidelines and given the ambiguity with respect to human rights in international guidelines, we demand that medical guidelines for people with VSC abide to any and all standards applicable in terms of human rights, in particular concerning the right to physical integrity, freedom from harmful practices, and right to health.

We recognise the guidelines published by the Accord Alliance in 2006 (translated by AISIA in 2012) as a first step toward inclusion of the human rights of people with VSC in medical practice. In particular, we specify that:

1. Sex characteristics must be considered protected characteristics and, as such, they must not be modified without personal consent, Consent for their modification cannot be provided by proxy figures such as parents, guardians, doctors, even when the individual is a minor.

2. VSC do not constitute a paediatric emergency.

3. Medical interventions in childhood must be primarily aimed at helping the family understand that their child is healthy. Any further intervention must be limited to early diagnosis and monitoring purposes, delivered in a respectful, non-stigmatising, and non-invasive manner.

4. People with VSC may require healthcare support throughout their lives, including due to medical interventions they underwent as children. The national health system must adequately support the health needs of adults with VSC, including through research, training, and the update of medical forms.

5. Standards of care should not require compliance with stereotypical norms of female or male bodies.

6. Alternative and independent oversight mechanisms must be put into place to monitor healthcare. These must be based on human rights and take into consideration the specificity of each case. For example, multidisciplinary teams that include human rights experts and VSC Organisation representatives alongside health personnel.

7. Minors with VSC should not be subjected to invasive examinations, particularly not in the presence of multiple professionals. Medical photography, in particular of private parts, should be avoided. These exams should be carried out with respect to their privacy and

awareness about the fact that they may have a negative impact on psychological well-being.

8. People with VSC must be ensured free access to their medical records, in particular during the transition from childhood to adulthood, also in order to improve transition of care.

9. VSC Organisations and peer support entities must receive appropriate funding, and must be involved in the development and deployment of healthcare and wellbeing processes.

10. The health and medical needs of people with VSC are sometimes related to the presence of a biological variation and sometimes not. The stigma associated with a variation, as well as prior stigmatising medical procedures can be barriers to healthcare.

11. National screening programs and IT systems must acknowledge the needs of people with VSC.

12. Communication about VSC provided during prenatal care and in the context of IVF must be updated and include non-stigmatising information.

13. Communication aimed at minors with VSC must become an integral part of healthcare protocols. This communication must be provided in an accessible, age-appropriate language, must be based on up-to-date, non-stigmatising information, and must be developed with the support of the VSC Organisations.

14. Data concerning VSC and relevant medical procedures must be recorded in a respectful and standardised manner across the country.

15. Clinical research must focus on the wellbeing of people with VSC. It must be informed by both the interdisciplinarity as well as demands advanced by VSC Organisations.

16. Healthcare professionals' training on the matter must be updated and human rights based.

17. Appropriate clinical transition pathways from paediatric to adult services that are informed, and promoted by those directly affected must be established.

6. TERMS AND DEFINITIONS

Variations of Sex Characteristics (VSC) is an umbrella term referring to people born with innate variations of their sex characteristics that do not fit the typical the binary medical and social notions of male and female bodies.
‘Sex characteristics’ refers to the elements of the body considered ‘sexed’, such as sex chromosomes, gonads, genetic markers, sex hormones, internal and external reproductive organs, genitalia and secondary sex characteristics.

Variations of sex characteristics are often referred to with other terms and acronyms, like ‘intersex’ and ‘DSD/dsd’, based on the disciplinary, activist and social context within which the variations are framed. The plurality of definitions today constitutes an unresolved terminological issue, and reflects a broader international debate about the legitimacy of framing variations as a medical emergency, psychosocial issue or human rights matter.
In the past, the term ‘intersex’ was used by doctors and scientists to define bodies whose biological sex was considered atypical. Nowadays, ‘intersex’ is widely used by people with VSC and endosex (people born without innate variations of sex characteristics) allies who promote recognition of VSC human rights. Even within the Italian context, ‘intersex’ is considered a better translation than ‘intersessuale’ (intersexual), in order to avoid confusion between innate variations and sexuality, identity, and sexual preferences.

Scientific literature tends to refer to each VSC with its specific clinical term, or utilise the umbrella term ‘Disorders of Sex Development (DSD)’. This definition was promoted in 2006 by a small group of academics, medical professionals, and a handful of intersex activists during the International Consensus Conference on Intersex in Chicago. The term ‘disorder’ was challenged early on by international intersex activism, as it carries within it the stigma of wrongness, a ‘disorder that requires correction. More recently, ‘disorder’ was replaced with ‘differences’ in medical literature as well, and is often shortened to the lower-case term ‘dsd’. That said, this change has not resolved the implicit reference to a ‘pathologically different body’, contributing to reinforce the social and medical prejudices surrounding the idea of what a male or a female body should be like.

In this context, distinct concepts such as biological sex, sexual orientation, gender identity, gender roles and expression have been historically confused with each other.
This results in medical interventions still being performed on the bodies of children with VSC with the idea of avoiding the social stigma associated with being trans or homosexual. People

born with VSC can have the same sexual orientations and gender identities as any other endosex person.

Variations of sex characteristics only involve the biological aspects of the body. However, sex assignment and ‘normalising’ procedures are generally driven, more or less explicitly, by the idea that the best thing for a child would be to develop into a cis-hetero-normative adult.

People born with VSC may also experience social violence aimed at policing their gender expression and role in accordance with binary, stereotypical behavioural frameworks, as well as heteronormative expectations.