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HEALTHCARE PROVISION FOR PEOPLE WITH INTERSEX VARIATIONS OF SEX CHARACTERISTICS

The information and recommendations provided in this eBrief are based on findings of the research projects developed in the framework of the INIA: Intersex – New Interdisciplinary Approaches Innovative Training Network.

Basic facts:

Intersex, and 'variations of sex characteristics' (VSCs) are terms used when someone has sex characteristics (chromosomal, gonadal, or anatomical) that are different from medical and social norms. According to the United Nations document 'Human Rights Violations Against Intersex People. A Background Note', up to 1.7% of the population has an intersex variation. This means that they have a body that does not conform to traditional understandings of male and female bodies. There is nothing inherently dangerous or unhealthy about having a body with a VSC.

People with VSCs are often subjected to medical interventions that can be experienced as traumatic, and can have an impact on their life experience, for example education due to sick leave or absenteeism.

International and European bodies have taken a stand against these treatments and surgeries. Also, several European countries (Germany, Iceland, Malta, Portugal, and Spain) have prohibited surgeries on children with intersex variations where they themselves cannot consent to it. VSCs have been shrouded in secrecy, stigma and shame. This has contributed to a widespread lack of VSC knowledge and understanding.

Language in this space is very contested. Within medical circles, VSCs have many diagnostic labels but are known as 'Disorders of Sex Development (DSD)' or 'differences of sex development' (dsd)'. Some people prefer to use terms like 'intersex' while others prefer to use medical terminology. In this brief, we use the term VSC to be inclusive of all perspectives.

What are the issues?

- People with VSCs are often subjected to medically unnecessary interventions that are experienced as harmful by many of those who have been subjected to them.
- Some healthcare professionals have responded to critiques with the claims of change in practice.
- Invasive medical interventions can cause considerable harm, and there is insufficient evidence for their use.
- Adequate and appropriate care provision is often lacking for this highly diverse population.
- There is still a lot of room for improvement in the healthcare currently provided to children, young people, and adults with VSCs.

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Current situation:

Intersex and variations of sex characteristics are complex phenomena. Support for children with VSCs and their families may require involvement of many different healthcare professionals, and peer support groups. Children with VSCs are born and raised in families with diverse class, race, gender, cultural and geographical backgrounds. Babies and children with VSCs are still often subjected to non-vital and irreversible interventions including surgeries which can have very harmful long term health impacts.

According to our research, current health care provision for specific and life-long needs of people with VSCs is often inadequate. There is insufficient knowledge, resourcing, and appropriate provision in general and specialist settings. The practice of surgical assignment of sex and gender on minors can cause problems with health and well-being later in life.

Psychological and social support is crucial for the parents and families of children with VSCs, especially before any irreversible medical procedures are performed. However, our survey showed that there is a pressing need for psychosocial provision. This should include trained specialists and provision of psychosocial support at the earliest point possible. People with VSCs who have been subjected to non-vital and non-consensual medical interventions may need ongoing support for medically induced trauma, but provision is lacking.

Good communication and provision of accurate information is essential for people with VSCs throughout the life-course, including parents and families of children with VSCs. Yet, our studies indicate that this is often not provided. A lack of transparency can lead to poor decision making and an unhelpful culture of secrecy. Necessary information about other sources of support such as peer groups and intersex NGOs is often not provided in medical settings.

Discrimination against people with VSCs can be a challenge in healthcare settings. Our research shows that this can include a lack of access to care, stigmatisation, and exploitation for teaching and research purposes. There are insufficient measures to address discrimination against people with VSCs in healthcare settings.

Recommendations:

- Ceasing non-vital medical interventions on those who cannot provide informed consent.
- Development of non-surgical care pathways for minors. Provision of resources to support young people with VSCs to make informed choices about their care once they are old enough to do so.
- Development of more sensitive and non-medicalising ways of supporting individuals and families, whether an individual has had medical interventions or not.
- The provision of high-quality specialist and individualized healthcare for all people with VSCs.
- Better communication and information provision to parents/carers and minors with VSCs. This should include information about intersex NGOs and peer support organisations.
- Training and professional development for medical and healthcare professionals including knowledge about bodily, sex and gender diversities.
- Training and support for mental health professionals and social workers that is directly informed by those with lived experience of VSCs.
- Support and renumeration for the active engagement of those with lived experience of VSCs in the process of healthcare improvement.
- Support and renumeration for the active engagement of those with lived experience of IVSC in the process of healthcare

About the INIA project:

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For more information, please check https://www.intersexnew.co.uk/

*We acknowledge that there are differences of opinion amongst INIA Consortium members and more widely amongst people with IVSC.

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