Indicative Policy Recommendations Concerning People with Intersex Variations of Sex Characteristics in the European Union

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 invisible within social policy contexts. Erasure of their concerns is very common in sectors including employment, education, social work, youth work, policing and community safety, sport and leisure, the media, and welfare provision more generally.

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 experience high levels of discrimination different social policy sectors. Outside of medical contexts, their existence is often overlooked.**
- **Within medical settings, the practice of medically unnecessary interventions has policy implications (e.g., on peoples' ability to contribute to the labour market) which are often overlooked, whilst appropriate care is often lacking.**
- **VSC issues are often overlooked in policy frameworks within EU member states, meaning that their needs are not met via equality, diversity, and inclusion interventions.**
- **Within different policy sectors, there is usually an absence of measures to address the specific needs and issues of people with VSCs.**
- **Where VSC people are included in policies, it is often alongside LGBT people. Whilst this can be useful, and some people with VSCs are also LGBT, it carries the risk that VSC people's specific issues are overlooked.**
- **Many people with VSCs do not identify as intersex, as having a VSC, or with groups such as LGBT people. There is a risk that they get overlooked by policy interventions if these are not inclusive.**

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 research provided by the INIA project, people with VSCs have been erased from policy frameworks and interventions at the most basic level –what is considered as a relevant policy issue. Social policies have assumed that there are only people with traditionally male or female bodies, and that only male and female genders exist. This means that VSC people may be overlooked by both mainstream and gender-specific policy interventions.

Research by the INIA team and others shows that appropriate health policies are crucial for supporting people with VSCs. However, policy work across other sectors is also central to supporting and including people with VSCs, and to tackling the discriminations they face. At present, insufficient provision exists to support people with VSCs in sectors including education, safety and protection from hate crimes, employment, sport and leisure, social work, and welfare benefits. The INIA research found that there is not enough policy work about people with VSCs across the lifecourse, with a particular lack of support for adult and older people with VSCs, and those with intersectional marginalities such as disabilities.

The research showed a pressing need for resourcing, education, awareness building, and training of policy actors and sector-level practitioners to enable them to support people with VSC.

Effective policies to support VSC equality, diversity and inclusion are being developed at transnational and in some cases national levels but implementation mechanisms are required across different sectors. These could include for example sector-specific impact assessments and monitoring of interventions.

It is crucial for policymakers to work together with people with lived experience of VSCs. Robust consultation and partnership mechanisms are needed, and resources are required to support this.

Whilst some of the issues raised by consideration of VSCs may be challenging, there is much to be gained by policies that support people with VSCs. There is a business case, as people who are able to live free from discrimination are more able to contribute to society and to avoid being a burden on welfare systems. There is also a social justice case, as the continued exclusion causes unnecessary suffering for people with VSCs and their families and communities.

Recommendations:

- Awareness raising, training and support for policy makers and those who implement social policies, across all sectors.

- Review of all policies at supranational, national, regional, and local levels to ensure that people with VSCs are included and that measures are present to tackle discrimination.

- Resourcing and capacity building across key sectors including healthcare, education, social work, public safety, and employment, to ensure that the specific needs of people with VSCs are met.

- Policy work to address the needs of adults, including older people, is particularly important due to insufficient work to date.

- Increased capacity-building and resourcing of social workers, psychologists, educators and other front-line practitioners to enable better support to families of those with children with VSCs, and people with VSCs, across the lifecourse.

- Care should be taken to include variation specific people (those who identify with a particular variation or condition) and those who identify as intersex. It is necessary for policy makers to be aware of the wide differences across different people with VSCs.

- Support and renumeration is needed for the active engagement of those with lived experience of VSC in the process of policy making and implementation.

About the INIA project:

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For more information and resources, 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 intersex variations.

**This brief reflects only the views of the authors, and the agency is not responsible for any use that may be made of the information it contains.

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