



OLDER INTERSEX PEOPLE

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 being intersex.

Intersex people with 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. I/VSCs have been shrouded in secrecy, stigma, and shame. This has contributed to a widespread lack of intersex knowledge and understanding.

Language in this space is contested. Within medical circles, I/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. Out of respect to the participants who provided this data, we use intersex.

What are the issues?

- Many older intersex people face barriers to adequate and appropriate healthcare such as avoidance of medical settings due to abusive experiences in medical settings and a lack of intersex-specific medical knowledge amongst medical professionals.
- Many older intersex people are especially vulnerable to loneliness and isolation sometimes due to family and/or community rejection.
- Variation and medical intervention related infertility contribute to isolation for intersex people in later life.
- Some older intersex people lack financial stability in later life for reasons such as employment discrimination and disabilities.
- Many older intersex people need mental health supports but them inaccessible due to financial cost and a lack of intersex awareness or competence amongst mental health professionals.
- While transgender and intersex are not the same, many older intersex people are also transgender and may face intersectional barriers to wellbeing including transphobia.
- Older intersex people have expressed fears of experiencing abuse and ridicule in eldercare facilities.

Current situation:

Many older intersex people experience loneliness and isolation due to stigma, shame, mobility issues, financial precarity, community and family rejection, and infertility. Some older intersex people have battled lifelong ostracisation hindering opportunities for socialisation and networking. Not being able to have biological families of their own due to variation and medical intervention related infertility exacerbates isolation in later life and can be accompanied by feelings of regret.

There is an urgent need for adequate and accessible mental healthcare for older intersex people. Rates of attempted suicide have been shown in recent studies to be much higher amongst intersex people than amongst the general public.

Many older intersex people face heightened financial precarity in later life due to a lack of social support and networks, family and community rejection, disability, injury, and employment discrimination. Some who have been bullied to the point where they dropped out of school may have been hindered by lower academic achievement.

Despite an increased need for care as we age, many older intersex people avoid care settings because of experiences of medical abuse and dishonesty as well as a lack of medical knowledge in care settings. Some older intersex people complain about experiencing worse treatment by medical personal when it is revealed that they are intersex, further discouraging them from seeking care in medical settings.

While intersex and transgender describe different phenomena, some, though not all, older intersex people are transgender and may therefore face related discrimination, violence, financial precarity and barriers to adequate and appropriate healthcare. Some older intersex people may face additional intersectional challenges if they are from other marginalised communities, i.e., Roma, Travellers, refugees, or asylum seekers.

Many older intersex people harbour fears of violence, discrimination, and humiliation in eldercare facilities from staff and other residents. Older intersex people that have no close family and are financially less secure may find themselves reliant on facilities run by religious organisation that hold views that could be considered irreconcilable with intersex wellbeing. Some regions, i.e., Zurich, are building eldercare facilities for older LGBTI+ people and conducting training and certification for eldercare facilities, setting an example worth following.

Recommendations:

- Development and provision of mental health and support services for older intersex people that are directly informed by lived intersex and transgender experience.
- Training and professional development for medical and healthcare professionals including knowledge about bodily, sex and gender diversities that is directly informed by lived intersex experience.
- Improved education and awareness training for medical professionals to increase access to testing and appropriate medical treatment for those with variations such as Klinefelter syndrome.
- Development of sensitive and non-pathologising ways for medical professionals, mental health professionals, eldercare workers and social workers to support older intersex people, whether an individual has had medical interventions or not.
- Provision of high-quality specialist and individualized healthcare for older intersex people.
- Training for mental health professionals and social workers that is directly informed by those with lived experience of being intersex.
- Training for those employed in eldercare facilities that is directly informed by those with lived intersex experience and certification for the facilities themselves developed with intersex organisations.
- Support and remuneration for the active engagement of intersex people in the process of healthcare and education improvement.

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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 VSCs.

**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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