

# The human rights of older intersex people

NNID Foundation

Call for input: thematic report on the human rights of older women

For: Claudia Mahler, Independent Expert on the enjoyment of all human rights by older persons

## Introduction

This submission is written in regard to older intersex people. Intersex refers to the experiences of people born with a body that does not fit the normative cultural definition of male or female. Research has shown that at least 1.1% of people are intersex.<sup>1</sup>

We request that intersex people are explicitly mentioned in the report when issues relating to them are discussed. While some advances have been made in recent years, intersex people remain mostly invisible in society as a strategy to avoid stigmatization. The limited available data indicates that even with attempts to remain invisible, intersex people have a significantly higher chance of being the victims of discrimination. The resulting social disadvantages and the chance of revictimization make this group particularly vulnerable in advanced age. However, the issues remain unaddressed as long as there is no awareness of the issues faced by intersex people, and specifically elderly intersex people. Explicitly stating that intersex people are experiencing specific problems increases their inclusion in international, regional, and national law, policies, and programmes.

## The rights of older women in international, regional and national law, policies and programmes

1. What legal instruments, policies and programmes exist to address the particular challenges faced by older women, and how are they implemented and monitored?

*There are no specific instruments for elderly intersex people in international, regional and national law, policies or programs. Such instruments are very limited for intersex people and those that exist are either general or aimed at young people. Older intersex people are often forgotten, while they regularly have more extreme experiences. Their experiences are dismissed as having occurred a long time ago. However, we should not forget that they still live with the results of these experiences. Some countries have included intersex in general anti-discrimination legislation.*

2. What type of statistical data are collected on older women, if any, and is it disaggregated by age, gender, and other relevant factors? How are older women defined for the purposes of law, policy and data collection?

*Little data collection has been performed regarding intersex from a social perspective. Due to the medicalization and pathologization of intersex, most studies come from the medical field. A limited number of studies from a social perspective were done in the past five years. Data collection is made more difficult due to a large number of intersex people being lost to follow-up. Around the year 2000, due to the rise of the internet, the secrecy surrounding intersex that health workers enforced was gradually eroded. Roughly between the 1950s and 1980s, in countries with an extensive healthcare system, it was common practice not to inform intersex people about being intersex. Regularly their parents were also not informed. It became common to surgically and hormonally alter intersex people to fit the sex-binary without their consent. As a result, many elderly intersex people still do not know they are intersex or know what happened to them as children. NNID has received anonymous reports from doctors who were unwilling to break the silence surrounding intersex forced on intersex people by their predecessors.*

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<sup>1</sup> Frisch M, Moseholm E, Andersson M, Bernhard Andresen J, Graugaard C. Sex I Danmark, Nøgletal Fra Projekt Sexus 2017-2018 (Sex in Denmark. Key Findings from Project Sexus 2017-2018). Aalborg, Denmark: State Serum Institute (Department of Epidemiological Research), 28 oktober 2019. ISBN 978-87-971732-0-6.

*Any studies on intersex have been limited in numbers. The most extensive social research is from Europe and included ca 5000 intersex respondents.<sup>2</sup> This study collected disaggregated data. However, due to the small number of respondents and geographical spread, an age-specific analysis has not been included. The second-largest statistical research on intersex people comes from a medical perspective with 1040 European respondents. However, this study excluded older intersex people.<sup>3</sup>*

*Older intersex people have systematically been excluded from research on intersex from a medical perspective, arguing that what happened was so long ago and medical practices have changed. There are no long-term studies of the effects of medical interventions on intersex people.<sup>4</sup>*

### 3. Please indicate how older women take part in participatory mechanisms?

*No data available.*

### **Economic, social and cultural realities lived by older women**

4. What are the specific challenges and concerns faced by older women, including on the basis of their accumulated life experience as compared to older men, in enjoying their economic, social and cultural rights (for example in terms of social protection, health, education, work, adequate standard of living, land and property ownership)? Please provide related data and statistics, including disaggregated data, where available.

#### **Health**

*As described above, for a long time intersex was almost completely invisible in wealthy societies due to secrecy. It is and was common for intersex people to be adjusted to fit the normative societal definition of male or female by non-consensual, unnecessary medical interventions, which include surgical, hormonal and psychological treatment. A 2020 study shows that 62% of European intersex people did not give fully informed consent for their surgical intervention themselves, nor did their parents give fully informed consent. 49% of respondents in the same study, or their parents, did not give fully informed consent for hormone treatment.<sup>5</sup> Due to strict secrecy, in the case of older intersex people these numbers of a lack of consent are probably significantly higher. Additionally, the procedures performed on them were often more invasive. These days a clitoris that is deemed too large by medical professionals is reduced in size. During the era of strict secrecy, amputation of the clitoris was common and still occurred until at least the 1990s.<sup>6</sup>*

*These interventions carry an increased risk of lifelong physical impairment or disability. While there is no indication of a medical background for intersex people to struggle with mental illness more than non-intersex people, intersex people are almost 4,5 times more likely to struggle with mental health. Suicide*

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<sup>2</sup> **European Union Agency for Fundamental Rights.** A long way to go for LGBTI equality. 2020. ISBN 978-92-9474-997-0. doi:10.2811/7746.

<sup>3</sup> **Falhammar H, Claahsen-van der Grinten HL, Reisch N, Slowikowska-Hilczar J, Nordenstrom A, Roehle R, et al.** Health status in 1040 adults with disorders of sex development (DSD): a European multicenter study. *Endocrine Connections*. 2018. <https://doi.org/10.1530/ec-18-0031>

<sup>4</sup> For the past decades, health professionals have argued that it is not useful to review practices from 10-15 years ago as new techniques are used. See for example: **Dokter, EMJ.** Hypospadias: From aetiology to prognosis of clinical and patient-related outcomes after surgical repair. 2019.

<sup>5</sup> **European Union Agency for Fundamental Rights.** A long way to go for LGBTI equality. 2020. ISBN 978-92-9474-997-0. doi:10.2811/7746.

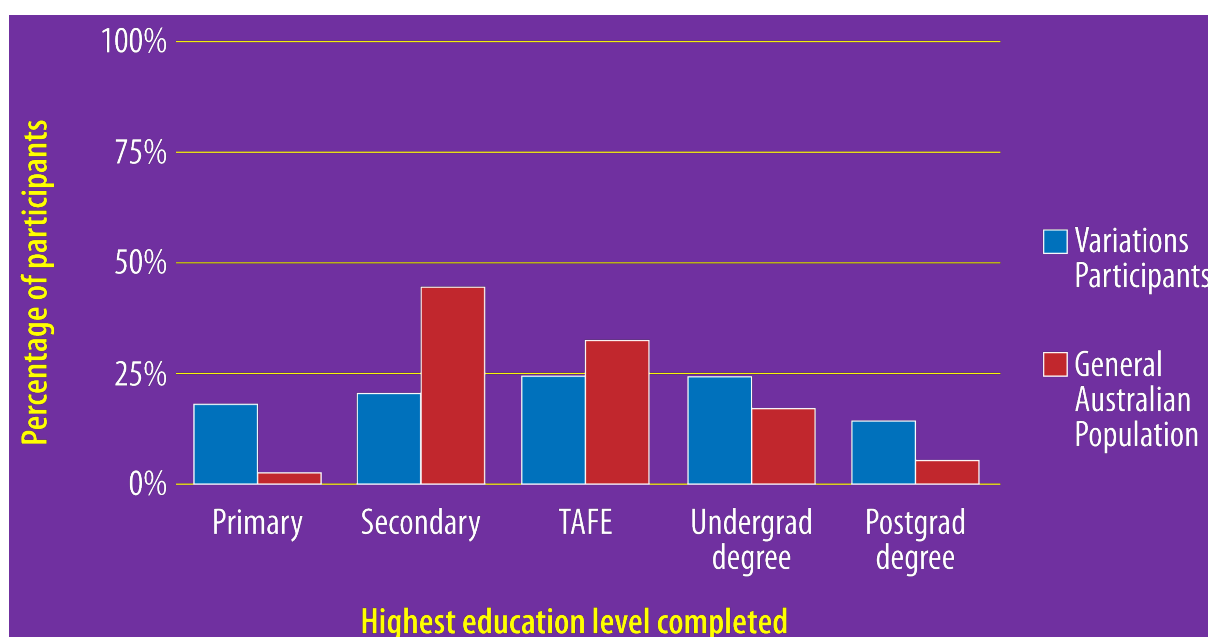
<sup>6</sup> *It should be noted that intersex organizations advocate that consent for non-urgent procedures to adjust their sex characteristics should only be given by the person themselves.*

attempts are 3.7 times more common.<sup>7</sup> The study by FRA showed that 35% of intersex people experienced discrimination in health care or social services settings in the preceding year.<sup>8</sup>

### Education

Currently, 50% of young intersex people in Europe experience bullying in school. While in general 36% of respondents experienced discrimination in school or university.<sup>9</sup> Research from Australia has shown that in spite of mandatory education, intersex people were ca. five times more likely to only finish primary education than the general public.<sup>10</sup> Also see Graph 1.

Graph 1: Education level difference between intersex participants and general Australian population.



Source: Jones T, Hart B, Carpenter M, Ansara G, Leonard W, Lucke J. *Intersex: Stories and Statistics from Australia*: Open Book Publishers; 2016.

### Discrimination

It is often assumed that intersex people experience discrimination less often than people who experience discrimination based on sexual orientation or being transgender. The special Eurobarometer showed that 53% of people think discrimination based on sexual orientation is widespread, 48% thought this was the case for being transgender, and 39% thought it was common for being intersex. However, the reverse is the case, as can be seen in table 1.<sup>11</sup> The European study by FRA has also shown that intersex people are most at risk of discrimination of all LGBTI-groups. 62% of intersex respondents experienced discrimination. 22 % of respondents experienced a physical and/or sexual attack in the past 5 years, and 38 % experienced violent in-person threats. Issues with obtaining identity documents also arise and 25% experienced discrimination when showing identity documents.<sup>12</sup>

<sup>7</sup> Falhammar H, Claahsen-van der Grinten HL, Reisch N, Slowikowska-Hilczner J, Nordenstrom A, Roehle R, et al. Health status in 1040 adults with disorders of sex development (DSD): a European multicenter study. *Endocrine Connections*. 2018. <https://doi.org/10.1530/ec-18-0031>

<sup>8</sup> European Union Agency for Fundamental Rights. A long way to go for LGBTI equality. 2020. ISBN 978-92-9474-997-0. doi:10.2811/7746.

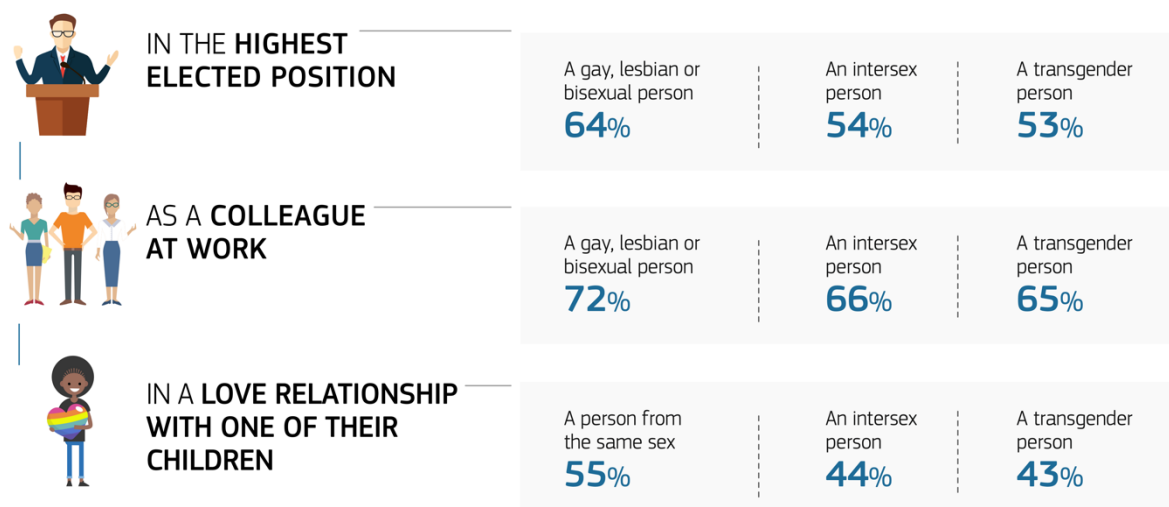
<sup>9</sup> European Union Agency for Fundamental Rights. A long way to go for LGBTI equality. 2020. ISBN 978-92-9474-997-0. doi:10.2811/7746.

<sup>10</sup> Jones T, Hart B, Carpenter M, Ansara G, Leonard W, Lucke J. *Intersex: Stories and Statistics from Australia*: Open Book Publishers; 2016.

<sup>11</sup> Special Eurobarometer 493 – “Discrimination in the European Union” Fieldwork: May 2019

<sup>12</sup> European Union Agency for Fundamental Rights. A long way to go for LGBTI equality. 2020. ISBN 978-92-9474-997-0. doi:10.2811/7746.

Table 1: Share of Europeans that say they would feel comfortable seeing:

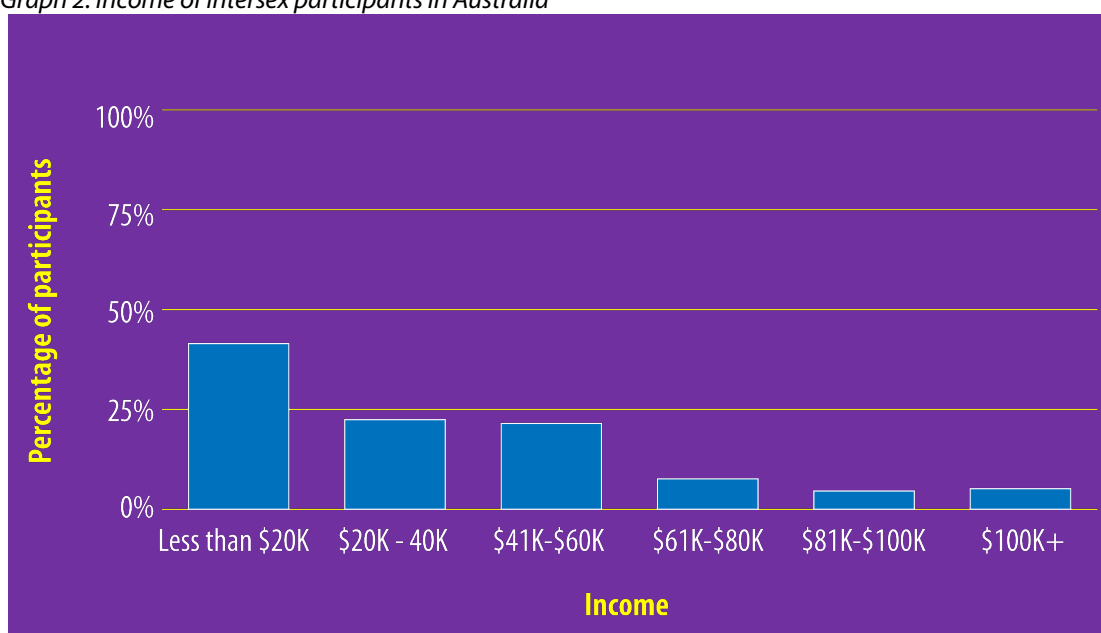


Source: Special Eurobarometer 493 – “Discrimination in the European Union” Fieldwork: May 2019

### Income and employment

Pathologisation of intersex, paired with other forms of discrimination, affect intersex peoples lives in their potential to find work and in their income. The Australian study also showed that 40% of participants had an income of less than 20.000 Australian dollars. If overtime and bonuses are included, Australia's average yearly wage was 80,054 Australian dollars per year at the time. Less than 10% of the intersex respondents in the study earned more than the average annual wage.<sup>13</sup> The European study showed that 51% of households that included an intersex person struggled to make ends meet. 27% of intersex respondents experienced discrimination when looking for work, and 32% experienced discrimination at work. As a result, 29% of intersex respondents have experienced housing difficulties in their lifetime, with 5% having slept rough at some point.<sup>14</sup>

Graph 2: Income of intersex participants in Australia



<sup>13</sup> Jones T, Hart B, Carpenter M, Ansara G, Leonard W, Lucke J. *Intersex: Stories and Statistics from Australia*: Open Book Publishers; 2016.

<sup>14</sup> European Union Agency for Fundamental Rights. *A long way to go for LGBTI equality*. 2020. ISBN 978-92-9474-997-0. doi:10.2811/7746.

Source: Jones T, Hart B, Carpenter M, Ansara G, Leonard W, Lucke J. *Intersex: Stories and Statistics from Australia*. Open Book Publishers; 2016.

**5. What forms of gender-based discrimination and inequality experienced by women throughout the life cycle have a particular impact on the enjoyment of their human rights in older age?**

*The societal effects of being born intersex, as described above, are likely to be specifically notable in later life in two aspects: the financial situation and the risk of mistreatment.*

*Issues such as limited access to education and employment, health problems, disability etc., increase the chance of intersex people being poor or even destitute in later life. It affects their opportunities to live comfortably, retire, and receiving the appropriate medical care. Additionally, intersex people are regularly born or made infertile by medical treatments. As a result, they are also more likely not to have offspring to care for them.*

*Intersex people have often experienced boundary-crossing behavior, such as bullying in school or threats and attacks against them. Especially problematic is the intersex human rights violations in the medical field. The rights to autonomy, self-determination, physical integrity and privacy have regularly been violated. Several intersex people have indicated that they have experienced part of these treatments as rape, and external sources have described practices that constitute sexual assault and abuse.<sup>15</sup> Becoming dependent on care is a concern for intersex people of all ages. NNID has specifically received reports from older intersex people who already dread becoming elderly and living in a care facility. They worry about having different people wash them, these people staring at their scars and either making remarks, or gossiping about them. Additionally, a background of physical, sexual or mental abuse, especially at a young age, puts them at higher risk of revictimization.<sup>16</sup>*

*For older intersex people who received treatment to make their body fit the sex binary it is often extremely difficult to access any data. Files have often been destroyed, lost or even stolen. It would therefore be necessary for medical files to be saved for at least the duration of a person's life.*

**6. Has the COVID-19 pandemic affected older women differently than older men and how?**

*In general, the COVID-19 pandemic has severely affected intersex people<sup>17</sup>. Traumatic medical experiences earlier in life contributed to the mental stress of the pandemic. Additionally, the pandemic unevenly affected people who did not have the privilege of education and formal employment.*

**7. Please share examples of how older women participate in and contribute to economic, social and cultural life, including inter-generational solidarity and support.**

*No data available.*

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<sup>15</sup> See for instance:

**Blair K.** When Doctors Get It Wrong. *Narrative Inquiry in Bioethics*. 2015;5(2):89-92. <https://doi.org/10.1353/nib.2015.0029>.

**Frader JE.** A Pediatrician's View. *Narrative Inquiry in Bioethics*. 2015;5(2):139-142. <https://doi.org/10.1353/nib.2015.0040>.

**Meoded Danon L.** Time matters for intersex bodies: Between socio-medical time and somatic time. *Social Science & Medicine*. 2018;208:89-97. <https://doi.org/10.1016/j.socscimed.2018.05.019>.

**Monro S, Crocetti D, Yeardon-Lee T, Garland F, Travis M.** *Intersex, Variations of Sex Characteristics, and DSD: The Need for Change*. Huddersfield, UK: University of Huddersfield, October 2017. Nr. 978-1-86218-151-9.

**Viloria H.** *Born both: an intersex life*. New York, NY, USA: Hachette Books; 2017.

**Nath S, Munkonge L.** Sexual ambiguity and malformation in Zambia: challenges in surgical management. *Central African Journal of Medicine*. 1995;41(5):161-166.

*No Box For Me. An Intersex Story*. Floriane Devigne. CFRT. France. 2018.

<sup>16</sup> **Widom CS, Czaja SJ, Dutton MA.** Childhood victimization and lifetime revictimization. *Child Abuse Negl*. 2008;32(8):785-796. doi:10.1016/j.chiabu.2007.12.006

<sup>17</sup> **Oii Europe.** COVID-19. A report on the situation of intersex people in Europe and Central Asia. Authored by Dan Christian Ghattas, with Irene Kuzemko. Questionnaire developed by Irene Kuzemko. Berlin. 2020. <https://www.oiiEurope.org/covid-19-survey-report/>

## Forms of discrimination against older women and gender-specific abuses

**8.** What forms of structural and systematic discrimination do older women face (for example through laws, policies, traditional and customary practices, etc.) and what measures have been taken to address them?

*See above.*

**9.** How do intersectional factors exacerbate the combined effect of ageism and sexism, including the perspective of older LGBTI women, older women with disabilities, older migrant women, older women belonging to indigenous and minority groups, etc.?

*The data shared at above indicates that the issues older intersex people experience can be exacerbated by intersection of discrimination based on (old) age and on being intersex.*

**10.** What forms does gender-based violence and abuse against older women take and how is such violence prevalent? Please share available data and statistics, including in relation to femicides.

*There are no known examples of older intersex people being killed for being perceived as a burden or worth less. However, in some area's infanticide occurs, and being outed as an intersex person is dangerous.<sup>18</sup>*

**11.** Please provide examples of how the life cycle perspective is integrated into policies and programmes to prevent and address gender-based violence against women and girls.

*No examples can be provided.*

**12.** Please share information about reporting, accountability, remedy and protective mechanisms available and targeted to older women victims of gender-based violence and discrimination.

*No examples can be provided, as described above, older intersex persons are often forgotten and ignored. They often do not have access to the documents they needs such as childhood health records, experience discrimination and stress over being dependent on a health care system again that damaged them physically and emotionally as children. Therefore, it is very important for older intersex people to be included in the report by the special rapporteur.*

### Contact information NNID

NNID Foundation  
Staddijk 91  
6537TW Nijmegen  
0031-24-3430000

### Contact person:

Annelies Tukker  
Policy Officer  
annelies.tukker@nnid.nl

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<sup>18</sup> **Grady H, Soy A.** The midwife who saved intersex babies. 4 May 2017. BBC News. <https://www.bbc.com/news/world-africa-39780214>  
**Singh P, Madurai, G.** Don't take their right to life away. 2 June 2020. The Pioneer. <https://www.dailypioneer.com/2020/columnists/don--t-take-their-right-to-life-away.html>  
**Collison C.** Intersex babies killed at birth because 'they're bad omens'. 24 January 2018. Mail & Guardian. <https://mg.co.za/article/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens/>  
**Benini, M.** Killed at Birth: the Slaughtering of Intersex Babies. 22 March 2018. Il grande colibri. <https://www.ilgrandecolibri.com/en/killed-intersex-babies/>