



Organization Intersex International USA

For intersex human rights, information, and peer support

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Submission to the National Institutes of Health Request for Information (RFI): Inviting Comments and Suggestions on the Health and Health Research Needs, Specific Health Issues and Concerns for Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) Populations

This submission provides information to assist the National Institutes of Health (NIH) in expanding its knowledge of the health needs and concerns of the intersex population and the cultural competency of researchers working with it. Intersex people are born with sex anatomy, reproductive organs, and/or chromosome patterns that do not fit typical definitions of male or female. This may be apparent at birth or become so later in life. Intersex status is not about sexual orientation or gender identity: intersex people experience the same range of sexual orientations and gender identities as non-intersex people. Intersex people face many of the same issues as other LGBTI populations.

1. Critical issues and impact

Intersex adults in the United States have long agreed that efforts to erase intersex traits from individuals and society via medically unnecessary, cosmetic genital surgeries and/or sex re-assignment surgeries of intersex infants and children (also known as “normalizing” surgeries) are a violation of the right to physical integrity. There is significant medical evidence of trauma and physical harm resulting from these medical interventions, as well as insufficient evidence that they are beneficial.¹

However, there has been a historic lack of engagement between medical specialists who promote and engage in these interventions and the patients subjected to them. For example, the 2006 International Consensus Conference on Intersex in Chicago, comprised of 50 international medical experts in endocrinology and pediatrics,² resulted in a change in nomenclature, adopting the term “Disorders of Sex Development/DSD” to refer to intersex people. While this change in terminology was presented as a consensus decision in the “Consensus Statement on the Management of Intersex Disorders”,³ only one intersex person participated, and numerous national and international intersex advocacy organizations, such as the Organization Intersex International (OII) -- the world’s largest intersex advocacy organization -- were not consulted in the creation of the

¹ Vilorio and Astorino (2013). *Your Beautiful Child: Information for Parents*. OII-USA. <http://oii-usa.org/wp-content/uploads/2013/05/Your-Beautiful-Child.pdf>

² I.A. Hughes, et al (July 2006). Consensus statement on management of intersex disorders. *Archives of Disease in Childhood*. Volume 91(7) 2006. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2082839/>

³ *ibid.*

“consensus” statement, and do not support the adoption of “Disorders of Sex Development/DSD”. DSD is not accepted by many intersex advocacy organizations because it pathologizes intersex traits and furthers the notion that normalizing surgeries should be employed to correct them.

In addition, despite reports that non-medically necessary interventions are harmful by dozens of the intersex adults subjected to them, the United States medical community continues to recommend them without sufficient concern for the rights of the intersex child and future adult, and without conducting follow-up research to determine whether the practices are beneficial. As a result, parents of intersex infants and children – who usually opt to have these interventions performed – lack necessary information in making decisions about their children’s bodily autonomy, regarding the medical and psychological risks involved, the lack of discussion of the option not to operate, and/or in an effort to address cultural biases.

It is critical to note that cultural biases and prejudice against intersex traits are responsible for the atypical health care described above. This is evidenced by statements such as the following by Dr. Kenneth Glassberg, considered a medical expert in intersex variations, in an interview with ABC’s *20/20*: “Society can’t accept people of different colors, and now we’re supposed to accept somebody with genitalia that don’t match what their gender is? I do not believe this society is ready for it.”⁴

2. Strategies for advancing the health of intersex people

We recommend that the NIH, health care providers and researchers working with intersex individuals be mindful not to perpetuate internalized prejudice felt by many intersex individuals by using stigmatizing terms which describe us as abnormal, diseased, or disordered, and/or dehumanize intersex people by portraying us as people with medical conditions rather than simply as people and equal members of society. We note that while it is currently common to refer to intersex people in this manner, other members of the LGBTI community were once also portrayed within this medical framework, such as gays and lesbians, who were defined as people with “psychosexual disorders” in the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM) until 1973.⁵ This framing of gays and lesbians as people with disorders did not serve to promote their human rights or self esteem, nor does it do so for intersex individuals.

In order to provide a healthy framework for parents of intersex children and those working with intersex individuals and their families, we published the educational

⁴ *20/20*. “Controversy Over Operating to Change Ambiguous Genitalia” (April 19, 2002). <http://www.youtube.com/watch?v=oHbBTEeayEU>. 2:49 minutes.

⁵ LGBT Mental Health Syllabus, *The Declassification of Homosexuality by the American Psychiatric Association* (2007). Group for the Advancement of Psychiatry. http://www.aglp.org/gap/1_history/#declassification.

resource, *Your Beautiful Child: Information for Parents*.⁶ It provides information not often made readily available, such as a comprehensive list of the few unbiased medical studies available on medically unnecessary interventions (all of which found that they are harmful), findings regarding the alternative of not choosing these procedures, and tips for how to communicate about intersex variations with friends and family. Further, it does so without using language which promotes stigma and/or perpetuates the notion that intersex traits are disorders in need of correction. Our other educational resource, *Brief Guideline for Intersex Allies*,⁷ provides basic information and answers to common questions about intersex people, as well as tips for how to promote awareness and acceptance.

We recommend these two educational resources to the NIH as a means for enhancing cultural competency regarding intersex people and engaging with the LGBTI health research and advocacy communities, and include links to them here: <http://oii-usa.org/wp-content/uploads/2013/05/Your-Beautiful-Child.pdf>; <http://oii-usa.org/wp-content/uploads/2012/10/Brief-Guidelines-for-Intersex-Allies.pdf>.

We also recommend that the NIH assist in the creation of protocols around “normalizing” surgeries which support medical findings and intersex people’s right to decide whether or not to undergo irreversible changes to their body, using the following guidelines, via OII Australia:

1. Medical intervention should not assume crisis in our difference, nor normalization as a goal.
2. Medical, and in particular surgical, interventions must have a clear ethical basis, supported by evidence of long term benefit.
3. Data must be recorded on intersex births, assignments of sex of rearing, and of surgical interventions.
4. Medical interventions should not be based on psychosocial adjustment or genital appearance.
5. Medical intervention should be deferred wherever possible until the patient is able to freely give full and informed consent; this is known as “Gillick competence”.
6. Necessary medical intervention on minors should preserve the potential for different life paths and identities until the patient is old enough to consent.
7. The framework for medical intervention should not infantilize intersex, failing to recognize that we become adults, or that we have health needs as adults.
8. The framework for medical intervention must not pathologize intersex people through the use of stigmatizing language.
9. Medical protocols must mandate continual dialogue with intersex organizations.

⁶ Vilorio and Astorino (2013). *Your Beautiful Child: Information for Parents*. OII-USA. <http://oii-usa.org/wp-content/uploads/2013/05/Your-Beautiful-Child.pdf>

⁷ Astorino and Vilorio. *Brief Guidelines for Intersex Allies* (2012) OII-USA. <http://oii-usa.org/wp-content/uploads/2012/10/Brief-Guidelines-for-Intersex-Allies.pdf>

10. In place of appearance-related genital surgeries on infants, the priority should focus on family support and counseling.

These guidelines were recently accepted by the Senate of Australia.⁸

In order to collect data on intersex people, we recommend amending forms and documents as follows:

Gender: --- M (Male) ---- F (Female) --- X (Unspecified/Intersex/Non-binary)

With an intersex history? Yes or No

Please note that the categories above allow intersex individuals who identify as males or females to do so, and those who identify as intersex to also do so, while still specifically collecting data for all intersex individuals. We also note that the inclusion of intersex individuals under the category of “gender identity”, as has sometimes been the case, is inaccurate and harmful as it perpetuates the erasure of intersex people as those with a congenital difference in biological sex, just as non-consensual surgeries have sought to accomplish.

We would like to thank the NIH for their request for information regarding the health and health research needs of the intersex community, and look forward to the continued inclusion of intersex advocacy organizations such as ours and others in their work to improve the health outcomes of intersex infants, children and adults. In addition, we note that we are volunteer run and unfunded at this time, and welcome funding opportunities from the NIH and others.

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About OII-USA: <http://oii-usa.org/978/oii-usa/>

⁸ Community Affairs References Committee, *Involuntary or coerced sterilization of intersex people in Australia* (2013) Senate of Australia.