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Key challenges to the human rights of intersex children and youth

Kitty Anderson
Secretary OII Europe

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Who does the term Intersex encompass?

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OII Europe uses the following defintion:

Intersex individuals are persons who do not match medical and societal norms of socalled female and male bodies with regard to their chromosomal, gonadal, endocrine or anatomical sex.
The latter becomes evident, for example, in secondary sex characteristics such as muscle mass, hair distribution and stature, or primary sex characteristics such as the inner and outer genitalia and/or the chromosomal and hormonal structure.
Simplifying working definition: We are intersex because our innate sex characteristics are either female and male at the same time or not quite female or male or neither female or male.
Although intersex people are born with intersex characteristics, intersex bodies can present themselves as intersex at birth, during childhood, in puberty or in adulthood. A person may realize being intersex at a very early age or later on in life.
People with intersex bodies may have an intersex gender identity or they may have any other gender identity

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What is Intersex?

- Sex Characteristics
- Primary: Outer and Inner Genitalia, Gonads, Chromosomes, Hormones.
- Secondary: Breast growth, Hair growth, Muscle mass, Stature, Fat distribution.
- 1/1500-2000 the number of children considered to constitute a social emergency, believed to warrant surgical intervention.
- 1/200, recent research points to the number of Intersex people to be as many as one out of every two hundred.

Gender Identity and Sexual Orientation

- Gender Identity.
  Intersex people can have any gender identity. Many are men and women and some identify outside the binary.

- Sexual Orientation.
  Intersex people can have any Sexual Orientation, with some being Straight and other Lesbian, Gay, , Pansexual or Asexual.Bisexual

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Key issues faced.

- Breach of Bodily autonomy and Physical Integrity

-Clitoral reductions

-Vaginoplasties

-Gonadectomies

-Hormonal Treatments

-Drugs administered pre natally and off label, despite research pointing to negative long term effects

- Secrecy-Stigma
  -Lack of visible role models
  -Often advised not to discuss their realities outside closed circles
  -Hard to find a community
  -Secrecy leads to shame

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The UN Convention of the rights of the child

Article 2

1. States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.

Article 3

1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

The UN Convention of the rights of the child

Article 7

1. The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and. as far as possible, the right to know and be cared for by his or her parents.

Article 8

1. States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference.
2. Where a child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to re-establishing speedily his or her identity.

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The UN Convention of the rights of the child

Article 12

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

Article 13

1. The child shall have the right to freedom of expression; this right shall include freedom to seek,receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.

Article 16

1. No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, or correspondence, nor to unlawful attacks on his or her honour and reputation.

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The UN Convention of the rights of the child

Article 19

1. States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.

Article 24:

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children

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Parental Decisional Regret after Primary Distal Hypospadias Repair: Influence of Family Variables, Surgery Variables, and the Outcomes of the Repair

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Parental Decisional Regret

- The Decisional Regret Scale, the Paediatric Penile Perception Score (PPPS), and the Dysfunctional Voiding and Incontinence Scoring System was administered to parents.
- Data was available from 172/372 families, response rate 46.2%.
- 128/323 (39.6%) parents presented with moderate-strong DR
- DR was unrelated to parental desire to avoid circumcision, surgical variables, development of complications, and duration of follow-up.
- Family variables seemed major predictors of DR, which was instead largely unrelated to surgical factors.
- Irrespective of the duration of follow-up, DR seems lower in parents of older patients.

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Shaping Parents: Impact of Contrasting Professional Counseling on Parents' Decision Making

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Shaping Parents

- The study was conducted at Zurich University Hospital, Switzerland, in 2011–2012, at the Institute of Biomedical Ethics at the University of Zurich liaising with the School of Applied Psychology at the Zurich University of Applied
- Groups shown one of two videos. A medicalised and de-medicalised information presented by a doctor and psychologist.
- 38/89“parents”(43%)chose early surgery for “their” child, including 27/41 “parents” (66%) shown the medicalised video vs. 11/48 (23%) shown the demedicalised video
- Indicator that changes in counselling services and information provided could lead to fewer parents opting for surgery.

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Subjective need for psychological support (PsySupp) in parents of children and adolescents with disorders of sex development (dsd).

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“during the first surgery I should have had help, but I was much too focused on my child to ask”

“I would like to have a contact person to get some advice for upcoming problems and fears in the future”

“someone who encourages me and stands by me during the period of uncertainty immediately after birth and in the first weeks”

“to be able to talk about concerns and fears before surgery”

“contact and exchange with other parents”

“psychological support at diagnosis immediately after birth“

“I needed somebody giving me confidence and information”

“Psychological guidance for the development of my child”

“in the first years I strongly desired psychological care”

“a cure”

What indicators do we have for quality of psychological support?

- 128 parents (40.4 %) indicated to have a need for PsySupp; 189 parents (59.6 %) reported having no need for PsySupp. The need for PsySupp could not be assessed in 12 parents.
- 128 Parents with a need for PsySupp Divided in:
  "We have received psychological counselling/ psychotherapy" 29/128 (22,7%)
  "We have received psychological counselling/ psychotherapy partly" 32/128 (35%)
  "We have not received but we needed psychological counselling/ psychotherapy" 67/128 (52.3%)
- Medical photography, radiography, laparoscopy, gonadal biopsy, gonadectomy and hormonal puberty induction are associated with a high need for PsySupp.

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What indicators do we have for quality of psychological support?

- No association between the need for PsySupp in parents and genital re constructive surgery could be found.
- There was no association between parents' perception of the appearance of the child's external genitalia, and need of PsySupp in parents
- There was no association between understanding the diagnoses and the need for PsySupp.
- 119/291 (40.9 %) parents reported that they did not completely understand the information about the final diagnosis 172 (59.1 %) parents did understand.
- Two hundred seventy (82 %) parents indicated that genital surgery of the child was recommended.

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Alexis parent of an Intersex child:
“The part that kills me today is the surgery . We’ve met a lot of people in the community that didn’t have any surgery done with their kids and, yeah, you know, I blamed myself . . . for many years, many years.
We should have left [our child] alone.”

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Katrin, mother of an Intersex youth:
"If I had known then what I know now I would have never agreed to surgery. Nobody told me that if her hormones were not managed correctly she would be in danger of Osteoperosis or that she would get so sick. Having a 19 year old already suffering fractures due to osteopenia and not being able to attend school full time due to undiagnosed chronic exhaustion and constant illness was not what I wished for my child. They just messed around with her hormones with no real explanations"