



INTERSEX, ETHICS AND MEDICINE

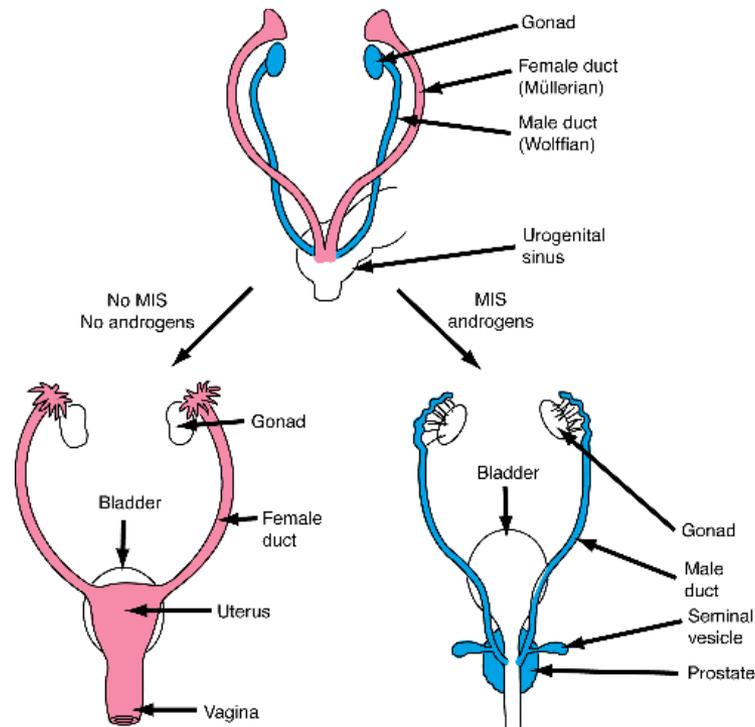
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What is intersex?

- "Umbrella term"
- Body's characteristics
- Can be also gender identity

Why is intersex?

□ Normal variation of sex characteristics



Why is intersex a problem?

- IS people do not fulfill our expectations and norms of dichotomous sex and gender
- IS problem is solved by medicalisation

Treatment paradigms

- Gender typical sex organs
 - If not → problems in parent-child attachment
 - prerequisite for sexuality
 - Essential for a normal psyche
- The child is a "clean slate"
- Sex + gender + upbringing

Means of treatment

- Gender typical sex organs by surgery
- Gender typical development by hormone therapy
- Gender typical behavior by upbringing

- Critique:
 - Do not take into consideration what we currently know about gender and child development

Reconstructive surgery

- Lack of data that surgery is beneficial (data on the problems of surgery)
- No studies support the belief that IS children require or benefit of early genital surgery
- No studies have linked early genital surgery to successful gender outcome
- No quality studies on whether gonadectomy, genital surgery or hormone therapies are safe for the children's gender health
- There is no scientific basis for predicting gender identity for IS children
- There is no scientific basis for predicting the sexual orientation of any children

Reconstructive surgery (2)

- As children are minors the parents have to give consent for these irreversible and potentially harmful surgical procedures
- While this consent may be legally possible it carries a substantial risk that the child's fundamental human rights for physical and psychological integrity and self-determination may be violated
- IS poses problems to ethics and law because there is the dilemma between the society's, parents, medical professionals' and the child's viewpoints

Surgery (3)

- still prevailing treatment protocols have proven to cause severe physical complications, chronic pain, loss of fertility, psychological problems, impairment of sexuality and sexual quality of life
- entails a high degree of uncertainty of gender identity, can result into a mismatch of assigned sex and later gender identity, produce stigma and feelings of shame, is distressing and traumatic

New treatment paradigms

Multidisciplinary team: experts on medical, psychological, legal, educational, social, ethical fields specially trained for care provision of these families

- Diagnosis including the normal aspects of the child
- Info on treatment needs, options and risks
- Info on health risks of intersex
- Info on legal matters as registration/change of sex now and later in life
- Info on IS challenges in puberty and adulthood

New paradigms (2)

- Info on dealing with social situations and upbringing
- Info on possible fertility and pregnancies
- Info on peer support and self-help groups, on-line resources
- Info/support according to the family's specific requirements
- The info should be comprehensive, understandable, individually tailored and unbiased
- There should be a balance between the medical and non-medical counselling

New paradigms (3)

- The parents' responsibility and authority of decision making is constrained by the child's well being, autonomy and competence
- The child's well being should be defined on the basis of the child's current interests but also on the future adult's anticipated interests
- As soon as the child gains capacity it must be involved in the process of decision-making but as children are prone to influence it should be ensured that the child does not feel to be under pressure from family or medical profession
- No cultural or family circumstance precede the child's autonomy or integrity
- All medical and surgical treatment decisions that have irreversible and substantial consequences that can be postponed should be deferred until later in life the person can decide him/herself

New paradigms (4)

- Two sex systems pose discrimination of IS children on grounds of sex and gender, which is against the laws in western countries
- The two sex system is based on custom - there is no compelling legal reason for this
- A third sex should be allowed and finally no indication of sex should be required when births are registered