

Case 7

According to rough estimates, 1 in every 1000-2000 infants born each year has ambiguous genitalia. These intersexed infants display various combinations of both female and male genitalia (e.g., an enlarged clitoris without a vaginal opening and with undescended testes).

According to the American Academy of Pediatrics (AAP), "The birth of a child with ambiguous genitalia constitutes a social emergency." Parents, understandably, are distraught, and the AAP notes that both the ambiguity of the child's sex and the parents' reactions to that ambiguity carry significant implications for the child's long term well-being. The most acute quandary is to determine whether the child will be raised as a girl or boy; in fact, parents are typically advised not to name the child or register the birth until the child can be assigned a sex.

Typically, genetic evaluations are undertaken to determine the infant's genetic sex (i.e., whether the child's chromosomal pattern is XX or XY) and the cause of the sexual ambiguity. Additional pediatric, urological, endocrinological and gynecological evaluations determine how best to assign potential fertility capacity for normal sexual function, endocrine function, potential for malignant degeneration, and intrauterine testosterone imprinting. Following sex assignment, surgical interventions are undertaken to revise the genitalia to conform to the selected sex.

While surgical reconstruction is not urgently required for medical reasons in most cases, the majority of pediatricians believe that sex selection should be completed as quickly as possible. Since parents and other family members, as well as members of society, interact differently with boys and girls; until the child's sex is established, say the pediatricians who favor immediate sex selection, interactions are likely to be stilted, stunted, aberrant, confusing, or discomfited. In addition to the distress of the parents and others, say the majority of pediatricians, the child whose sex is undefined may experience ostracism and suffer from confused self-identity and self-understanding.

This assumption, and accordingly, the propriety of early surgical correction, has come under increasing challenge. Medical ethicists have recently argued that, as intersexuality is seldom threatening to life or health, the surgery should be postponed until the person who will be most affected -- the intersexed individual -- can give autonomous consent. Moreover, autonomous consent requires a full explanation of burdens and benefits, the nature of which have yet to be determined. In opposition to the assumption that early treatment is always in the child's best interests, intersexed adults have begun to come forward to report various harmful effects of early surgical intervention. For example, first-person accounts testify to the pain and loss of trust that arise upon learning that one's parents and physicians have deceived them about the nature of one's gender. This loss of trust is often accompanied by a perception that the deceit stems from embarrassment or from seeing the intersexed person as a "freak." Further, surgery that involves reducing the size of a penis or clitoris often results in loss of sensation and of orgasmic capacity.