

## Intersex condition and the construction of gender identity

Paola Miano  
University of Palermo, Italy

### Abstract

*Intersexuality is conceptualized as a disorder of sexual development (DSD), which includes congenital conditions associated with atypical chromosomal, gonadic and anatomic sexual development. DSD can be diagnosed at birth as a result of observation of ambiguous genitalia, or, in adolescence, if sexual development diverges from the assigned gender. Some DSD can only be recognized in adulthood as a consequence of reproductive difficulties. In children and adolescents with DSD, gender identity is strongly influenced by atypical sexual development. The comparison between two management models of DSD, the optimal gender policy and a holistic perspective focused on the individual, highlighted their differences with regard to effects on individuals with DSD.*

**Keywords:** Intersex, Disorders of Sex Development, Gender identity, Psychosocial management, Coping.

## **Typical and Atypical Sexual Development**

Sexual differentiation is a complex process, with clear sequences and occurrences that starts at the beginning of foetal development and comes to an end at puberty (Rugarli, 2005). According to Fausto-Sterling (1989) the sexual differentiation process is influenced by the presence of the Y chromosome and should be analysed in a complex model; molecular biology research underlines the fact that the Y chromosome alone is actually not enough to produce a male individual (Schiebinger, 2008). As emphasized by Rosario (2009), the Mendelian theory of inheritance is not appropriate for sexual development, because there is not a perfect and rigorous correspondence between a specific gene and a specific trait; in fact more than one gene is involved in the sexual differentiation process and at least fourteen genes are considered crucial in sexual development (Cotinot, Pailhoux, Jaubert, & Fellous, 2002).

The intersex condition is characterized by atypical chromosomal, gonadic and anatomic sexual development and it represents an element contradicting the binary male/female differentiation. The various types of intersexuality are diagnosed as Disorders of Sex Development (DSD) and individuals with an intersex condition show atypical sexual development. The sexual development model should bear in mind that it is not correct to assert that in the absence of the Y chromosome there will be a feminization process. The theory that considers the presence or the absence of the Y chromosome as the key element in sexual developmental, even if is not correct, is closely linked to a cultural dimension in which masculinity is associated with an active character, while passivity is connected to femininity, as in Aristotle (Jost, 1947): “it is the male who contributes the active component that leads to the greater vital heat necessary for the formation of a male foetus. If the father is healthy and not too young or too old he will produce stronger, more active male semen that is more likely to prevail over the female material and thereby generate male offspring” (Rosario, 2009, p. 273).

Intersexuality could be better explained through a complex model of sexual development that provides for male individuals, female individuals and intersex individuals. Subjects with an intersexual condition show something atypical in their sexual development; when there is atypical sex chromosome development it is possible, for instance, to have a complete or partial absence of the second sex chromosome, as in individuals with Turner syndrome who have a XO karyotype. Atypical gonadic development could lead, for instance, to the formation of an ovotestis, i.e. a gonad containing testicular and ovarian tissue; additionally, anatomic sexual development could result in a micropenis in subjects assigned to the male sex.

When a newborn child shows ambiguous genitalia the intersex condition can be recognized at birth and it is possible to choose the best sexual assignment for the child. If an intersex condition is identified during adolescence or adulthood clinical tests are required for a DSD diagnosis and it is usual to have indicators such as virilisation after puberty in a female adolescent or infertility in an adult female. In any case treatment should focus on adjustment strategy.

With DSD being so varied, treatment for individuals with an intersex condition should be individualized, although it is indispensable to follow the guidelines for each syndrome (Morland, 2008). DSD has quite a low frequency in the general population and the main diagnosis has a low estimated incidence (Blackless, Charuvastra, Derryck, & Fausto-Sterling, 2000): 0.0922/100 for the Klinefelter syndrome (XXY karyotype), 0.0369/100 for the Turner syndrome (XO karyotype), 0.00760/100 for the complete androgen insensitivity syndrome (CAIS or Morris syndrome),

0.000760/100 for the partial androgen insensitivity syndrome (PAIS) and 0.00770/100 for congenital adrenal hyperplasia (CAH).

Gender identity is one of the most important issues in an intersexual condition. The construction of gender is influenced by social factors and the social community represents a crucial variable in defining gender norms, role expectations and appropriate behaviour. Gender stereotyping tends to convey rigid images that are almost impossible for simple human beings to attain; we are supposed to be perfect men and women if possible, at ease with everything, ready to cope with all difficulties. According to Eagly & Wood (1999) gender stereotypes are risk factors for non-intersex subjects and we can therefore consider them as high risk factors for individuals with DSD, in particular with regard to psychosocial wellbeing, social acceptance, body satisfaction, close relationships, sexual gratification and available health services (Warne & Raza, 2008).

When a DSD diagnosis is made in infancy or in adolescence the whole family organization is involved in tackling the intersex condition. DSD entails processes of self construction and concerns both the person with DSD, his/her parents and other siblings; sexual in-determination in children or adolescents with an intersex condition might actualize oedipal dynamics and consequent conflicts. The main reaction to the DSD diagnosis in the family system consists in what Michel, Wagner & Jeandel (2008) called a conviction with two functions: a defensive one and an organizational one (Rajon, 1998). Furthermore, the stage in life cycle psychology in which the family discover the intersex condition is crucial; sexual ambiguity is always a disturbing element and is potentially traumatic. Parents might have been expecting a male or a female and are then not prepared to have a child with an intersex condition; additionally, persons with DSD often have a feeling of discomfort with their personal and gender identity (Dreger, 1998; 2006).

Hegarty (2000) underlines the fact that reactions to an intersex diagnosis depend on gender identity rigidity; the more stable the gender construction, the more traumatic might be the DSD. In any event, a DSD diagnosis does not always have negative consequences and for some individuals the intersex diagnosis could improve readjustment and reduce symptoms of psychological disorder; individuals may find a name for what they have always felt and may find a coherent reason for their difficulty in accepting themselves and for their ambiguous feelings about gender and sexual identity.

### **Managing a Sexual Development Disorder**

Intersex conditions are extremely varied and their aetiology ranges from genetic to anatomic and hormonal causes; different aberrations in embryonic differentiation processes induce specific diseases with different symptoms. We can identify two main typologies of treatment distinguished by their theoretical framework, procedure, family involvement, evaluation of personal and social variable, short and long term effects. The first approach is indicated as optimal gender policy whereas the second is a holistic treatment focused on the individual.

The optimal gender policy is a theoretical and therapeutic model developed by Money (1975) to manage intersex cases; according to this model persons with DSD should be treated with a surgical intervention that will adapt external genitalia to the assigned sex. A further element concerns the timing of the intervention, since the sooner the operation is performed the more likely it is that the intervention will be effective. The optimal gender perspective was utilized for the first time at the Johns Hopkins Hospital, between the 50's and 70's, with the aim of assigning the child to

the sex that would better correspond to his/her external genitalia. The principal criterion for sexual assignment is genital appearance, since ambiguity is considered a severe obstacle to the adjustment process and gender identity construction is seen as a flexible development until the age of two years.

The best-known case treated with the optimal gender policy is the John/Joan case (Money & Ehrhardt, 1972; Money & Tucker, 1975; Money, 1975); John was a 7 month-old child whose penis had been burned by an electric scalpel during a circumcision operation resulting in a total ablation of the penis. Because of this accident Money recommended changing gender assignment, switching from male gender to female gender and proceeding with genital feminizing surgery. John's parents pondered Money's advice for ten months and then they decided to follow Money's advice: John underwent genital surgery (orchiectomy and reshape of scrotum to labia majora) and was raised as a girl in line with a female role and typical gender expectations. According to 8-year follow-up data Money (1975) asserted that the new John/Joan's identity was well-adjusted, did not present psychological problems and her development was comparable to that of her monozygotic twin. Data on John/Joan's adjustment were rejected by Diamond & Sigmundson (1997), who found that at 6 years John/Joan opposed female gender re-assignment; subsequently he remembered the medical examinations with anger, described surgery as a traumatic experience and was teased and threatened by peers (Kipnis & Diamond, 1998). At 14 he opted for the name of David, instead of Brenda, and in adulthood he lived appropriately, in accordance with a male gender role, married a woman and adopted her children.

The optimal gender model considers gender as a developmental element that could be changed during the first two years of life, without negative effects; gender identity construction is evaluated solely as a cultural outcome that is not defined before the third year of life and can be changed: biological development during pregnancy is underestimated, while gender social roles are overrated.

Reflecting on the David Reimer (John/Joan) case and in particular on its outcome (severe depressive symptoms and a suicide in 2004 at the age of 38), some researchers have underlined the need to determine a different model for handling DSD. These studies led to a second theoretical model that also lays down treatment guidelines and outcome variables to be evaluated.

The second model might be defined as a full-consent policy (Wiesemann, Ude-Koeller, Sinnecker, & Thyen, 2010) focused on the individual and emphasizing certain dimensions: specificity of different DSD, biological correlates, effects of genital surgery, global wellbeing outcomes, relational security, gender identity and sexual functioning and satisfaction. The importance of the latter variable, which explores whether people are at ease and content with their assigned gender and with their sexual life, was strongly emphasized by Chase (1998) and Crouch, Minto, Liao, Woodhouse, & Creighton (2004), who judged sexual functioning as one of the most important elements to be taken into account. To have established the priority of preserving sexual functioning and keeping nervous tissue intact, is very innovative if we consider that according to the optimal gender model male and female genital functioning is evaluated by focusing on potential peer discrimination (for instance because of a micro-penis) or on vaginal adequacy with regard to penetration (Slijper, Drop, Molenaar, & de Muinck Keizer-Schrama, 1998).

This approach characterizes the activity of the Intersex Society of North America (ISNA), which in 2008 changed its name to Accord Alliance; this organization focuses both on how people

with DSD perceive their condition and on genital surgery outcomes from the individual's perspective. Accord Alliance activity helped subjects in an intersex condition, with their families and their partner offering advice to cope with developmental tasks. In 2006 a critical document was drafted by two important paediatric endocrinologist associations (Hughes, Houk, Ahmed, Lee, & LWPES/ESPE Consensus Group, 2006) and established guidelines on DSD management. Consensus Statement on Management of Intersex Disorders took into account the lack of data and the varieties of DSD and, in spite of this complexity, the authors were able to identify effective and flexible clinical strategies for avoiding social stigma; a subject in an intersex condition should not be assigned to one sex before specialists have given their evaluation; subjects with DSD and their families should be openly and fully informed about intersex conditions and predictable effects; their opinions and emotional reactions should be taken in account. Furthermore, treatment should be chosen on the basis of their capacity to avoid gender dysphoria symptoms: "factors that influence gender assignment include the diagnosis, genital appearance, surgical options, need for life long replacement therapy, the potential for fertility, views of the family, and sometimes the circumstances relating to cultural practices" (Hughes et al., 2006, p. 152). Another important issue concerns those intersex conditions that need to be treated with surgery due to a risk of neoplasia; in all other cases surgical intervention should be postponed until the person with DSD can take responsible decisions.

### **Families with a DSD Member Facing Decision-Making on Treatment**

The Consensus Statement on Management of Intersex Disorders (2006) led to an essential reflection on different treatment and obliged medical staff and families to think short and long term effects through. On these bases Wiesemann, Ude-Koeller, Sinnecker, & Thyen (2010) reported the results of the German working group "Bioethics and Intersex" within the German Network DSD/Intersex, which tried to put together the perspectives of clinicians, individuals with DSD and families. One of the main principles regards the medical aspect of DSD: "the appearance of the external genitalia in DSD generally causes no medical problems or immediate health threats to the child" (Wiesemann et al., 2010, p. 673), so that it is suggested to wait until the age of 5 or 6 for minor interventions and until the age of 12 or 14 for the major ones. A surgical moratorium until the age of consent could help to avoid surgery that does not confirm identity gender in adolescence and adulthood. From the same standpoint the ambiguity of expressions that evaluate ethical reasons is stressed: what are the best interests of the child? Are they always the same one for everyone? Would a very anxious parent be more inclined to choose a surgical solution? Would being faced with ambiguous genitals be more difficult for an excessively firm parent? And what do we mean when we talk about the ultimate best interests of the child? (Chase, 2003; Diamond & Beh, 2006; Miano, 2011).

In any event parent-child relationships should be protected and parents' reactions to DSD are among the most significant variables in the wellbeing of children with DSD. Parents and family members should be supported in accepting the intersex condition during the whole developmental process. Thus the 9 principles and recommendations of the German working group advocate "a shift in paradigm from optimal appearance and potential functioning to optimal emotional and social development trying to maximize the child's and future adults' participation in decision making on one hand and a good parent-child relationship on the other" (Wiesemann et al., 2010, p. 675).

Another issue is stressed by Davidian (2011), who wonders whether parents and guardians should have the authority to consent procedure that implies sterilization and loss of genital tissue

and consequently the possibility of enjoying sexual relations. Intersex activists, by comparing intersex surgery with female genital mutilation (FGM), aim to bring human rights issues into the debate. The author states that this comparison failed in its purpose because of cultural reasons; FGM is considered a cultural practice whereas genital “cosmetic and normalizing” surgery is evaluated as a standard medical practice; instead of comparing genital surgery with FGM, it would have been more useful to compare it with male circumcision since they are both performed in order to enable children to meet their society standards and to be accepted by their community (Jurgensen, Hampel, Hiort, & Thyen, 2006; Frader, Alderson, Asch et al., 2004). This analogy makes it easier to understand the weight of social pressure with regard to gender identity and body appearance: “the need and desire to be socially accepted and understood cannot be overstated” (Davidian, 2011, p. 14). Bodily integrity is, therefore, a focal element in the intersex debate, but it will be hard to dispute parental consent as long as genital surgery is evaluated as a standard medical practice.

It seems that initial parental reactions to a DSD diagnosis have considerable influence on future decisions based around their own intuition, the appearance of external genitalia, the imaging reports of gonads and genetic testing results. Parents’ descriptions of DSD management reflect their emotional state and astonishment; parents view surgery as the only alternative “the minute he was born, here he had this – it has to be fixed... It was never any question whether he was gonna go through the surgery or not (...). We really never had to make a decision... the doctors told us what was gonna need to be done” (Crissman, Warner, Gardner, Carr, Schast, Quittner, Kogan, & Sandberg, 2011, p. 4-5). Nevertheless, doubts, anxiety and fears remain after surgery and with particular concern regarding gender identity and role, genital appearance, sexual function and couple relationship. Moreover there are constant worries about sharing the information with others; parents are troubled by the social stigma, by viewpoints about who has the right to talk about the DSD and the feelings associated with providing communication about DSD. Therefore, secrecy and privacy should be balanced out with the opportunity to receive social support and to choose with whom to share information (Crissman et al., 2011).

From a qualitative perspective Sanders, Carter & Goodacre (2011; 2012) emphasize, on the one hand, that, after childbirth, parents describe events and diagnosis as confusing and chaotic, and, on the other hand, that it is difficult for parents to protect their children from other people’s intolerance or curiosity. They try to prevent their children from being teased by not talking about the DSD and this attempt is associated with idealized expectations about the effects of surgery. Parents sometimes regret giving their consent for surgical treatment and feel as if they have abandoned their child: “there was no discussion about not having surgery, as she believed that surgery was essentially a solution that was able to completely fix complex genital issues: but you know, it was fine because he just told us what we wanted to hear which was...yes we can fix this” (Sanders, Carter, & Goodacre, 2007, p. 3192).

Coping was identified as a significant variable in evaluating family adjustment to DSD by de Medeiros Rocha Santos & Cavalcanti Ferreira de Araujo (2008); they recognized five typologies of functional or dysfunctional coping strategies in a group of caregivers of children with DSD (3 mothers and 1 grandmother): 1) before gender assignment the child is called by a gender neutral name; 2) caregivers do not expose the child’s body; 3) the gender assigned is considered definitive; 4) treatment is chosen by participating in the decision-making process; 5) children are left free to explore gender roles or 6) on the contrary, children are reprimanded or punished if they behave like

children of the opposite sex. In addition, parents provide advice on how to tackle social difficulties, reply to indiscreet questions and respond to peer teasing. As a consequence of this reflection it is stressed that psychological support must be continuous and addressed to all family members and is intended to help parents to enable their children to explore gender roles and gender expression through various toys, friends and attitudes.

The variety of coping strategies shows how they can have either positive or negative short- and long-term effects on individuals with DSD and their families (McCubbin, McCubbin, Patterson, Cauble, Wilson, & Warwick, 1983). Research by Duguid, Morrison, Robertson, Chalmers, Youngson, & Ahmed (2007) confirms that parents are often anxious about social stigma, but also about actual surgery and related anaesthesia. It might be interesting to underline that parents usually opt for treatment that avoids the teasing of children, but they do not associate the risk of stigma with surgical delay.

Furthermore, in order to take decisions about treatment, parents have to cope with DSD in the various developmental phases of their children. Hullmann, Fedele, Wolfe-Christensen, Mullins, & Wisniewski (2011) focused their research on five different stages (infancy and toddlerhood, preschool age, school age and adolescence) and analysed two variables in parenting capacity: parental overprotection and parenting stress; these two variables, moreover, could be taken as a measure of adjustment within the parent-child relationship. Parental overprotection indicates dysfunctional behaviour since caregivers tend to protect their children even if it is not necessary to protect them; parenting stress concerns the stress related to a parenting role. Both of these elements are associated with negative outcomes in emotional, behavioural and social adjustment and these negative outcomes get worse in children with chronic illnesses (Hullmann, Wolfe-Christensen, Meyer, McNall-Knapp, & Mullins, 2010). It is interesting that researchers found similar rates of stress and overprotection in parents with children in an intersex condition and parents with children with type 1 diabetes mellitus (Fedele, Kirk, Wolfe-Christensen, Phillips, Mazur, Mullins, Chernausek, & Wisniewski, 2010).

Parental overprotection seems to decrease as children grow up and overprotection during infancy and toddlerhood is higher than in the control group; on the other hand, during adolescence parental stress scores are significantly higher than in the control group and concern the parental role: "I feel trapped by my responsibilities as parent (...) Most times I feel that my child does not like me and does not want to be close to me" (Hullmann et al., 2011, p. 5).

Early surgery decisions do not prevent parents from facing gender dysphoria symptoms that might emerge during infancy, adolescence or later. In some cases children with DSD do not feel at ease with their assigned gender and wish to live in the opposite gender; it is very challenging for children in an intersex condition and their caregivers to differentiate between a real desire to live in the opposite gender and a predictable need to explore both feminine and masculine behaviour (Meyer-Bahlburg, 2008).

### **Families with a DSD Member Confronting Short and Long Term Effects**

Surgical intervention represents one of the major issues regarding the intersex condition. On the one hand the optimal gender policy emphasizes the process of normalizing the intersex body and tends towards early surgical intervention in order to assign or re-assign children to the sex with the best adjustment prediction; from this viewpoint specialists use terms such as corrective surgery.

On the other hand surgical intervention is viewed as potential genital mutilation if subject with DSD does not actually seek it.

Feder recognizes a link between homosexuality de-pathologization and intersex de-pathologization, and identifies another way of reflecting on DSD; taking a perspective that could help to choose the best treatment for each individual: “rather than fight for the demedicalization of intersex conditions that indeed have consequences for individuals’ health, acceptance of this change can transform the conceptualization of intersex conditions from their past treatment as disorders like no other to disorders like many others” (Feder, 2009, p. 227).

Focusing on children and adolescents with DSD within their families, is it possible to identify characteristics that help subjects to cope positively with the intersex condition. As happens with other non-normative life events (Walsh, 2008) the meaning that each member of the family finds in each event changes the experience. In particular, we can recognize three factors involved in understanding the intersex condition and supporting individuals with DSD: gender stereotypes, emotional skills and sense of security.

Gender stereotypes define gender roles, behaviour and expectations regarding an individual, based on the individual’s gender; cognitive processes are influenced by stereotypes. Subjects with an intersex condition have an assigned sex that is not always well-matched with gender identity and often individuals with DSD report a mild or severe discomfort with regard to their gender (Schweizer, Brunner, Schützmann, Schönbucher, & Richter-Appelt, 2009). While transsexual subjects might not feel at ease with their sex because they feel they belong to the opposite sex (Witten, 2003), individuals in an intersex condition are often uncertain about their gender; DSD is frequently associated with Gender Identity Disorder (GID) and with the feeling of insecurity regarding one’s gender. Rather than a certitude that life would be better after a sex-reassignment, individuals in an intersex condition are often insecure and doubtful about their gender. There are periods (either short or long) in which they feel more male, others in which they feel more female and others still in which there is no prevalence in gender identification. We might suggest that the more rigid the gender stereotype, the more likely a gender identity disorder. Therefore, in a family system, we might affirm that the more rigid the gender role, the more difficult will it be to cope with an intersex condition; flexibility and the capacity not to be frightened by uncertainty are essential conditions (Melby, 2002).

Emotional skill is the second factor that could help in confronting an intersex condition. By expressing and managing emotions we increase our capacity to understand our inner world and that of others; in an intersex condition both the individual with DSD and his/her principal caregivers have to cope with strong emotional responses. Intersex conditions place individuals in a complex position with regard to their identity; for individuals with DSD it is often difficult to identify themselves as either male or female, to establish their sexual orientation and to establish their gender identity in order to have satisfying relationships with other individuals. In the unexpected event of a DSD diagnosis the person involved will tend to feel depressed, angry, shocked, disappointed and could suffer from a wide range of negative emotions. Subjects with high levels of reflective functioning are able to identify their emotional reactions and those of others; they can distinguish one emotion from another, give a name to each of these, accept both positive and negative effects and modulate negative effects in order to handle them more effectively (Fonagy, 2007). Therefore, dealing with an intersex condition will be easier for those who have higher



mentalization skills, which might help them to accept the DSD and to adjust to the intersex condition.

Another focal point in dealing with an intersex condition is the sense of security that individuals with a DSD might perceive as a resource. Subjects in an intersex condition often report that they have been rejected by parents, family and friends because of their condition (Chase, 1998); occasionally caregivers might be so upset about their children's uncertain gender situation, so scared about how their children might develop, so overwhelmed by the issue of identity, that they are unable to maintain an acceptable and close relationship. On the contrary, other subjects with DSD report warm relationships with their principal caregivers and friends and underline how crucial it was for them to feel the sense of acceptance, love and security received from others; more specifically, it seems that a sense of security is associated with better adjustment and overall psychosocial wellbeing (Hegarty, 2000; Miano, Granatella, & Garro, 2011).

### **Conclusions**

The issues of parental responsibility and parental consent to genital surgery regard various elements: emotional reactions, coping strategies, gender role, cultural issues. In this complex theoretical framework, parental legitimacy to authorize surgery is associated with potential iatrogenic harm as regards severe potential outcomes such as sterilization, infertility and loss of sexual pleasure (Gurney, 2007). A philosophical perspective might help in understanding how individuals, families, medical staff and communities perceive DSD and to promote a positive image of the intersex condition. Grabham (2012) highlights a theoretical issue concerning the conceptualization of the body and poses the question of timing in connection with surgery: "understanding the social and ethical effects of surgeries requires addressing the relationship between corporeality and temporality. In other words, surgeries, and their effects on bodily integrity, can and should be theorized as temporal phenomena, or at least as processes heavily influenced by ideas of time" (Grabham, 2012, p. 6). She wonders if it might be more correct to consider the body, before and after genital surgery, as two different bodies, or if it is preferable to perceive the body after surgery as reframing new features. Terms like to fix, to normalize and genital cosmetic surgery arise from an ideal body image in which everything should exist in a specific and exact manner; despite this fact, studies on reconstruction demonstrate that re-establishing wholeness (as a result of a malformation or an amputation) could have negative effects and could damage one's self-identity. After structuring a positive personal identity and a satisfying self-image (independently of objective body appearance) surgery treatment engenders interruption, rupture, breakage and disjuncture, which are always associated with dissonance: "even if it is accepted that genital surgeries cause temporal interruptions, the implication here might be that these are interruptions of otherwise happy and healthy corporeal time-lines" (Grabham, 2012, p. 16).

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