Human Rights and Gender Identity: The Process of Developing a Booklet For Families of Intersex Children

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Amongst the various challenges faced while studying intersex matters, there is the defiant discussion of sexuality and gender. In this special issue there are certain dimensions of wholeness and integrity of the individual which cannot be ignored. One of these dimensions is the approach in human rights. However, every intersex child's birth confronts the family and the multidisciplinary team with a sticky situation. This article aims to analyze the process of developing a booklet for families with intersex children. The methodology of this article draws upon the collection of graduate research procedures for the development of the content. The interviews done in Salvador, Bahia, Brazil with intersex youth and adults, their families, health and social service agents such as psychologists and legal professionals were gathered together to create the booklet. The booklet is a mild form of communication for families of intersex children introducing them to scientific information. This work paves the way for further discussions concerning the principles of human rights and of the psychologist's role in its provision. Future directions include a matrix that fills the training practice and the research—an approach of professional experience in a mostly interdisciplinary perspective—with the family. Facing the challenges of the family with an intersexed child, the involvement of a psychologist in an interdisciplinary team is decisive and irreplaceable.

The main purpose of this article is to analyze the interdisciplinary process of developing a booklet for families with intersex children. Intersexuality reveals the complex nature of gender and involves anatomy and sexual congenital reproduction that deviates from what is socially expected of men and women (Canguçu-Campinho, 2012; Canguçu-Campinho, Lima, & Souza, 2015). The features that define male and female bodies are mixed when it comes to the intersex body.

It is understood that cultural contexts play a significant role in defining gender and sex. Bodies are perceived within cultural scripts that determine what sex "should" belong to, and consequently, what gender is expected. Seen as a cultural construction, gender is shaped by prevailing views that dictate the different ways to define oneself in the world.

According to Butler (2007), sex and gender are seen as something unnatural, with their supposed discursive and cultural linearity questioned. To talk about gender involves considering the constant changes in the social sphere and the characteristics of the self.

Gender identity is defined by a sense of belonging to a particular gender; it involves internal and external dimensions of the subject. "The sense of the self is constructed at the intersection between the individual and the collective, and culture plays a crucial role in this dynamic" (Canguçu-Campinho, Bastos, & Lima, 2014, p.3).

The dynamics of the self in intersex people involve multiple voices and silence in the I-positions that end up "sometimes legitimizing to the traditional view of sex and gender setting, stressing the similarities of organisms in respect of social and cultural patterns of normality, defying, sometimes, the traditional view of sex and gender by emphasizing the differences between these standards" (Canguçu-Campinho, Bastos, & Lima, 2014, p. 18).

Although studies indicate that one baby is born with intersex every 4,500 births (Vilar, 2009) there are stull no statistics gathered that are related to this phenomenon in Brazil. The birth of intersexed child impacts in distinct forms each family. However, the intersex condition presents the challenges of overcoming trauma and facing the concept of a sexual binary. In this learning dynamic each family happens to become acquainted with subjective aspects of its history. It may further think of sex versus gender as a social phenomenon, which approximates the individual of other issues not previously considered.

Intersexuality involves different body conditions that, to a greater or lesser extent, weaken the claims made about sexual binaries. The answer to whether it's a boy or a girl, which is often asked about the birth of a child, is lagging behind in certain intersex conditions. The question brings whispers, hushes, strange looks and sometimes uncertainty as to how best the family must deal with it. (Crissman et al., 2011). Since the issue concerns the identity of the child, it also affects his/her dignity, and therefore all children's rights.

SILENCE DIMENSIONS: FAMILY AND INTERSEX

Intersexuality is a subject that remains hidden from society in Brazil (Canguçu-Campinho, 2012). Its exposure is limited, many times, to the nuclear family and to a few professionals. The lack of immediate knowledge of the child's sex contributes to and social invisibility and to making the birth of the child traumatic for the family. This experience turns the confidentiality pact between the family and the health care professionals most intense. According to Canguçu-Campinho (2008, 2012), this covenant is done to ensure that the emotional integrity of the intersex child is preserved through privacy and secrecy; however, this leads to isolation and social invisibility of the intersex person. The secret creates a certain lack of awareness, and because of its own weakness, lack of awareness, eventually, causes a traumatic experience to some families.

Knowledge and practices relating to intersex matters are still limited to individualized logic and technical terms of experts. With this background of the biomedical hegemony, human rights principles are restricted in practice.

In Latin America, and more specifically in Brazil, health professionals utilize technical jargon from another language that the family is accustomed to. Scientific literature concerning the intersex condition is not understood by the main stakeholders: families and the intersex person. The many academic fields supply different insights on the intersex condition. Despite what was proposed by the Chicago Consensus of 2006, there is no agreement on the terms regarding intersex matters.

In Brazil, the terms Sexual Anomaly Development (ADS acronym in Portuguese) and Sexual Development Disorder (DDS acronym in Portuguese) are common in both areas of scientific research, as well as in health assistance to the intersex. Maciel-Guerra and Guerra-Junior (2010) use the term DDS and talk about the importance from etiologic diagnosis to define the sex of the child and the need of standardizing the information provided to their families.

However, families and intersex people misunderstand the nomenclature used by health care professionals, and frequently refer to the condition of intersex as "a small problem" or as a "defect" (Canguçu-Campinho, 2008). Besides the lack of coherence between the terminology used by health care professionals and the language used by families, there is a hierarchy of medical power. The power of that authority represents for the family the subject of intersexuality inside a frame. Medical language lessen the possibility for the families to express languages of its own to face the circumstances of the new baby. The family language of fear, anguish, fragility and the vulnerability do not have much room due to that powerful medical language.

The medical power within the topic gender identity is not often discussed. It deepens the lack of social awareness about intersexuality and, on the subjective level, impacts the dynamic of defining gender identity. Besides the lack of consciousness, there is a silence—a common practice amongst the families of the intersex children. (Lima, Campinho, Guimarães, & Souza, 2015)

This non-dialogic relationship reveals unequal participatory levels, since there is little participation in decisions that directly involve the child. In this context, in which information makes authorization strength to promote dignity, a booklet was published in October 2014 for families of intersex children.

BACKGROUND

The pamphlet "Dignity of Children in Intersex situation: guidelines for the family," whose main crucial point is the dignity of the child, was developed in 2014 and written after much research and interaction with the families served by genetic services. "Dignity of intersex children: guidelines for the family" (Canguçu-Campinho & Lima, 2014) was the result of much collaboration between the authors through different exchanges with psychology, law and public health, including strong support of the families of intersex children. It sought to fill a need for developing information in writing.

The development of this material was based on conversations, covering more than two decades, between households of intersex children and the authors. Both authors had experience about intersex issues from their professional background.
A meeting between the two writers in 2004 in a clinical for genetic ambulatory of the university hospital which provides service to intersexed individuals was the first step forward in this interdisciplinary project.

The first author is a psychologist and part of a team in a specialized clinic in intersexuality, mainly composed of doctors from different specialties. She is also involved with public health by making use of her professional experience and cumulative knowledge from her Master's and a PhD in Public Health (ISC/UFBA).

The second writer is a registered nurse and expert in law. She served as a judge for fourteen years, has a PhD in Public Health, developed a project for the rights of intersexed children in 2004, and coordinates a research group of Human Rights, the right to health and family, and the clinical special outpatient services Genetics.

The clinic has become a reference for the provision of services to the public and to provide the necessary space for interaction.

The content of the booklet intentionally written in a plain language, includes the comments of the research group called "Human Rights, Right to Health and Family," created by Lima in 2002, whereas the Catholic University of Salvador is accredited by CNPq (National Technological Advice and Scientific Development). The pamphlet also includes information about the Center for Studies and Practice for Intersexuality (Institute of Psychology - IPS/UFBA) created by Canguçú-Campinho.

DEVELOPING THE BOOKLET

The methodology used in this study is qualitative; it includes a reviews literature and a report from the brochure preparation process. Larger scale meetings, as well as work subgroups were conducted for developing the booklet. Eighteenth meetings have taken place in order to develop the content, enhance interdisciplinary and accessibility, and provide spaces for operational meetings for formatting the booklet.

The writing involved knowledge and practice from different professional areas, such as psychology, public health, law, medicine, social work and design. Dialogue among the disciplines allowed us to understanding the birth of the intersex child as an event that, although not occur naturally traumatic, can be experienced as such, depending upon the socio-cultural context.

Taking into account the possibility of experiencing a traumatic event, human dignity has become a core principle in the development of the booklet. The booklet sought to improve upon: technical reductionism, promoting the simplicity of the communication within the family and pointing out stressful life components identified during the provision of health care services for this population.

The handbook, written in Portuguese, has the potential to be translated into other languages. It tells the tale of a family with an intersex child. The storyline consists of presenting troublesome situations lived by the family members and provides possible solutions. All the circumstances narrated in the stories are based on the real life contact with the families during the daily work experience of the authors.

Among these circumstances are 1) the moment when one mother, referring to her family, describes her children and the birth of one of her babies in intersex condition; 2) the time when the mother hears malicious comments from neighbors about the status of her baby; 3) a family encounter with the doctor after the result of exams; 4) an appointment with families already experiencing this situation for a longer period; 5) the moment that family will register the child at the registry office; and 6) the meeting with the social worker to find out about the legal and communal resources for rights protection.

METHODOLOGY

The methodology used to preparing the booklet involved four phases.

The first phase was the identification of cultural and scientific problems in this subject by a review of literature, documents and movies, including fiction books, blogs and documentaries on intersex people.

One survey of health care institutions was undertaken to identify measures which protect the dignity of intersexed children. Letters were delivered by email to the 26 State Departments for Health and the Federal District. Contacts were identified in the institutions that make up, according to the law, entities entrusted with the integral protection of children, and, therefore, providing support for intersex children, such as the Public Defenders, the Child Protection Agency and the Public Prosecutor of each capital of the 26 states in Brazil.

During the first stage a survey was carried during the year of 2014 to identify all kinds of medical examinations required to diagnose the intersex condition. They were categorized for the kinds of exams, biological material collected for the exam and the examination was available via the SUS (the Brazilian universal health care system) or by private doctors.

In the second stage, a booklet was created using the collected data and ideas discussed in groups. The handbook content, formatting, and graphics were also discussed.

At this stage, the main aim of the designer was to create art materials supplying the booklet's message with precision and a manner consistent depicting characters in the story and sceneries in Accordance with regional characteristics.

In addition to the accessible language and the explicit reference to the difficulty of access to health care service, either by distance or by poverty, one of the points of the booklet was to make reference to the African descendant's features. It also refers to the suitable costumes of the region and points out the main difficulties whenever facing the professionals attending at the civil registration desk.

The third stage was the booklet validation by having a variety of people read and comment on the brochure. This group included those who have recently had intersex infants and those who are of a different domain.

The first project was accomplished by professionals from diverse fields of knowledge, as well as people who were familiar with the subject and those with the lowest formal education.

The handbook has also been validated by two families whose kids were born during this period in intersex condition. The family members felt they learned by reading the material presented to them, which meant that the booklet had been understood.

The fourth stage was to determine strategies for promotion both for printed copies and in a virtual environment, with the major institutions that provide health, social and juridical services, as well as families of intersex children.

WORKING TOWARDS THE DIGNITY OF THE INTERSEX CHILD

In accordance with our bibliographical research we did not find any booklet tailored just for families with intersexed babies. Therefore we can say that this brochure is the first of its type designed in Brazil for families of intersex children. Its content has been created considering the importance of ensuring the dignity of the human being as a basic principle of human rights.

Intersexuality is a complex subject and requires the construction of knowledge. So this booklet was the result of an innovative approach and an interdisciplinary process. Cooperation between various fields as psychology, law, and social services allowed the culmination of knowledge about intersexuality that does not belong exclusively to any of the disciplines alone because it was interpreted and gathered through an interdisciplinary dialogue. It was because of the exchange of knowledge and the professional experience of the authors in providing services for intersex people and their families that the booklet was possible. Thus, the task of writing in an accessible way for families, bearing in mind the sensitive nature and scientific importance of the issue, benefitted from the authors' experience and their collaborators team.

The new approach of knowledge suggests a new understanding of gender identity of these children that goes beyond the polarized view of self versus others. Thus, the authors believe that the construction of self in gender identity does not occur separately from the influence of social configurations (e.g., family, neighbors, friends, teachers, colleagues).

The family is usually seen as both a catalyst in the formation of the child's gender identity and dignity and as a promoter of the child. The interfaces between the voice of the family and other social voices in the absence of a representative one from the parents and the child's body are all catalysts in developing the gender and the identity of the intersex child. So satisfying the child about his or her gender is directly related to two issues. The first issue is how the family perceives and treats the child. The second aspect is about the series of actions taken by the family in order to ensure respect for dignity, uniqueness, and the rights of the child.

Affection and child care are crucial components for promoting of the child's dignity. It follows that “to take care of” involves plans for the happiness and the role that caregivers play in those plans. The quality of the relationships established amongst the family, the child, and healthcare professionals is reflected on the creation of more robust forms to all aspects of health for these individuals (Canguçú-Campinho, 2012).

Gender identity is regarded in this material as united with providing human dignity and human rights. The family, which provides a framework for the child’s development of the child, is also seen through the lens for the promotion of dignity. The prospect of promoting dignity in the publication takes place of both the convention on children's rights (UN, 1989), to which Brazil is a signatory, and the Constitution of Brazil and the legal set of this country. Dignity is therefore understood as the completeness of the being the child's condition.

The booklet's contents will also benefit from guidance from the law field for the purpose of changing a common practice of the families, as pointed out by Lima (2006), of getting "help" initially from politicians (i.e., councilors, mayors and congressmen) of their city to ensure the exercise of their legal rights. Thus, the booklet also comprises models of documents with emphasis on five specific themes: 1) support for children's health; 2) medications requested from the Department of Health; 3) application when being away from home and to the Department of Health; 4) a generic model for the ombudsman of the Child; and 5) issues concerning the civil registration of intersex child. All of this is also addressed by suggesting an alternative to the creation of a special temporary registration. For this registration, the child's name and sex would not be required, which would not interfere in the child's guaranteed rights.

The document also provides some clear definitions as a foundation for this field. Gender involves psychological and social characteristics assigned by the society to each sex. Certain cultures assign some behaviors, thoughts, and feelings as appropriate to boys, girls or others. Gender identity is the personal feelings and perceptions of gender. Fear is the emotional reaction that happens when someone feels threatened or endangered. The danger may be real or imaginary. Fear is not always related to life-threatening, but matches mostly to the perception that we are vulnerable. This perception is affected by personal and social factors and depends largely on the culture and environment in which we grow up in (Canguçú-Campinho, & Lima, 2014, p.44).

MAIN CHALLENGES AND ACCOMPLISHMENTS

The intersex condition often brings to light the limited ability of health care services to accommodate intersex children from a human rights perspective, the weak family support policies and the lack of communication among social actors in the system charged with ensuring the protection of the child in Brazil. A major challenge in preparing this material is to make it a tool for dialogue about human rights education, contributing to the training of health professionals, family members, and public officials, among other social actors that deal with children.

The initial challenge in the development of the booklet was to define its main purpose and target audience. It was decided, initially, that because this first booklet would be directed towards family members, it would have less content of a technical nature, and would speak to family members in a clear way so that the message conveyed would be effectively understood.

One big challenge was to determine the characteristics of the booklet and its textual content. An informal writing style was chosen to reflect the reader's reality. Thus a brief fictitious story was created, expressing the anxieties, fears, and feelings experienced by these families. One of the situations is depicted by the interference attitude and of the neighboring gossip. The main goal of this strategy was to facilitate the identification of families of intersex children with the characters in the booklet.

Another challenge was to produce a text that was representative of the dialogue among the various professional fields and that used clear and accurately language. This challenge mainly involved the development of interdisciplinary knowledge. To accomplish this, the authors put their professional experience into the service of intersex people and their families, and also integrated their observations ans results of research conducted over more than two decades.

The differences between the doctors and professionals in the fields of the humanities and the applied social sciences, was latent, beginning with the term "intersex." According to the doctors, "intersex" should have been substituted by "anomaly of sexual development" or "disorder of sexual development." The principle of the dignity of the child guided the decision of the group to use the term "intersex." The terms DDS or ADS were thought to cause the feeling of shame and to contribute to the families keeping secret the child's situation, with all of the interpretational baggage associated with the words "disorder" and "anomaly" that are derived from a normalizing measure of what is normal versus pathological (Canguilhem, 2002).

BREAKING THE SILENCE, PROMOTING DIGNITY

The main goal of this booklet was achieved, since this material became an important tool to break the silence and contributed to the promotion of the full health and dignity of the intersex person. Silence has diminished in the circles that the dialogue has reached. Ultimately, this booklet also reflects upon the child's right to health, the interfamilial relationships and the institutions tending to the children, affecting their dignity (Lima, 2002). This silence also reveals certain subtleties about health services and their policies (Lima, 2002; Testa, 1997). The increased dialogue amongst families, between families and the intersex child, or even between families and health professionals, is a possible consequence of access to the booklet by the different social actors.

Concepts such as hermaphroditism, intersex, gender identity, karyotype, and genital "ambiguity" are presented to the readers, contributing to demystifying the intersex condition. Making reference to the mythological dimension and shifting of the pathological perspective brought about with hermaphrodite myth, son of Hermes and Aphrodite. This view of the phenomenon of transcendence was also developed through a scientific approach in language accessible low-education families. The authors and the team of collaborators, represented by the third author of this article, strengthened the bond of theoretical-conceptual integration and have produced more after creating this didactic material grounded in a commitment to the dignity of the each child.

The booklet is a health communication tool that can be used as a guide for promoting health in the context of intersexuality, and also as an instrument to guarantee the rights of the intersex child, facilitating the work of guardianship directors, child and youth prosecutors, as well as social workers, public defenders and magistrates.

The publication can also be accessed and used as educational material for human rights, and is available to other professionals such as healthcare professionals, midwives, doctors, nurses, nursing staff, psychologists and teachers of primary schools, among others in the community. This interdisciplinary effort in connection with the reaffirmation of moral status of intersex people child is totally in line with the principles that provide the framework for the United Nations Convention on the Rights of the Child.

CONCLUSION

The first two subtitles highlighted the aspects of invisibility, silence and trauma involving intersexual children and their families. The intention was to show how parents deal with the birth of their intersex child. Any child who does not meet the so-called heterosexual society expectations, represents, among other aspects: silence, secrecy, invisibility, and trauma to parents and family.

The intersex infant´s birth raises doubts, curiosity, gossips and rejection from the very moment of his/her birth because it´s still a taboo and a rare occurrence. It is discussed as happening due to the child not having fulfilled what was expected from those around him. In other words, though they love their children, parents, in general are not ready to face the impact of the newly born intersex child or do not really agree with what is done to make the child fit into either a female or male, socially established, frame.

Family in general predicts the suffering that the intersex child will possibly experience in the process. Nevertheless, they cannot do much to avoid it; the parents' tendency is to protect the child from painful situations. What is clearly agreed is that intersex children usually do not conform to society's fundamental assumption that there are only two sexes and therefore, only two types of normal bodies that fit into the world. The word trauma in the above description makes reference to the family common feelings and reactions due to the birth of an unexpected intersex child.

By describing the background and the many phases during the development of the booklet, the authors intend to show their interest commitment and contribution towards society and especially in favor to the family of intersex children in order to build up the dignity that children and their families deserve. The research team also shares the obstacles, challenges, and accomplishments of the journey.

Knowing that no effort was in vain, the authors of the article intend to continue working to diminish uncertainty, doubts, pain and embarrassment for the parent and the intersex children who look for the clinical services. The main objectives of the booklet was not to talk about behavior of families of intersex children, and a second edition is expected to give space for them to speak by themselves.

To summarize, all of the adults attended and interviewed expressed concerns about how badly they feel about ignoring their children's condition. They agreed to take part in this study in order that their experiences could help others who deal with intersex children and have no clues nor experience about it. These parents also feel victimized either by the surgery process or the medical management.

As a matter of fact, the lack of communication, non-disclosure and secrecy issues between the doctors, parents and the intersex child has only caused intersex adults to experience unnecessarily feelings of inadequacy, isolation and confusion. Therefore, it is time to end with such unnecessarily suffering. For that we will keep on struggling in order to break the silence, the invisibility and the trauma; bringing instead a new and refreshing understanding of what intersexuality is really about. It is the Human Rights purpose, and it is our truly commitment to follow the Convention on the Rights of the Child (UN, 1989).

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