

**WHAT DIVERSITY ARE WE TALKING ABOUT? INTERSEX BABIES, THEIR FAMILIES, AND THE CHALLENGES OF EARLY CHILDHOOD EDUCATION**

***DE QUE DIVERSIDADE ESTAMOS FALANDO? OS BEBÊS NA CONDIÇÃO INTERSEXUADA, SUAS FAMÍLIAS E OS DESAFIOS DA ESCOLA DE EDUCAÇÃO INFANTIL***

***¿DE QUÉ DIVERSIDAD ESTAMOS HABLANDO? BEBÉS EN CONDICIÓN INTERSEXUAL, SUS FAMILIAS Y LOS DESAFÍOS DE LA ESCUELA DE EDUCACIÓN INFANTIL***



Isabella Regina Gomes de QUEIROZ<sup>1</sup>  
e-mail: isabellaqueiroz@bahiana.edu.br:



Silvanne RIBEIRO-VELÁZQUEZ<sup>2</sup>  
e-mail: silvanneribeiro@gmail.com



Carlos Alberto Ferreira DANON<sup>3</sup>  
e-mail: cafdanon@gmail.com

**How to reference this paper:**

QUEIROZ, I. R. G. de.; RIBEIRO-VELÁZQUEZ, S.; DANON, C. A. F. What diversity are we talking about? Intersex babies, their families, and the challenges of early childhood education. **Plurais - Revista Multidisciplinar**, Salvador, v. 9, n. esp. 1, e024003, 2024. e-ISSN: 2177-5060. DOI: <https://doi.org/10.29378/plurais.v9iesp.1.19397>



| **Submitted:** 20/12/2023

| **Revisions required:** 25/01/2024

| **Approved:** 03/02/2024

| **Published:** 12/07/2024

---

**Editors:** Prof. Dr. Célia Tanajura Machado  
Prof. Dr. Kathia Marise Borges Sales  
Prof. Dr. Rosângela da Luz Matos

**Deputy Executive Editor:** Prof. Dr. José Anderson Santos Cruz

---

1 Bahiana School of Medicine and Public Health (EBMSP), Salvador – BA – Brazil. Psychologist and Doctor in Medicine and Human Health (EBMSP). Adjunct Professor at the Bahiana School of Medicine and Public Health.

2 Federal University of Bahia (UFBA), Salvador – BA – Brazil. Doctor in Educational Psychology (University of Barcelona). Post-doctorate in Early Childhood Literacy Studies - Benemérita Universidad Autónoma de Puebla/Mexico (BUAP). Adjunct Professor at the Faculty of Education (UFBA) – Department I.

3 Bahiana School of Medicine and Public Health (EBMSP), Salvador – BA – Brazil. Doctor in Medicine and Human Health (EBMSP). Adjunct Professor at the Bahiana School of Medicine and Public Health.

---

**ABSTRACT:** The aim is to reflect on the difficulties faced by parents of babies living with the most common intersex condition, Congenital Adrenal Hyperplasia (CAH), highlighting the challenges of integration into early childhood education (ECE). It's a retrospective analysis of narratives using qualitative documentary methods. It revisits data from a doctoral study that investigated the perceptions of healthcare professionals and parents regarding babies born with this condition. The focus emerges from family narratives and the challenges they encounter in dealing with schools based on their lived experiences. It acknowledges the legal framework as an important tool for inclusion, but the social and political implications within the prevailing context perpetuate the invisibility of these children. It concludes that the redesign of ECE for effective inclusion demands intersectoral action involving various stakeholders, particularly the children.

**KEYWORDS:** Intersex condition. Babies. Early childhood. Education. Diversity. Family.

**RESUMO:** O artigo pretende refletir acerca de dificuldades sofridas pelos pais de bebês que vivem com a condição de intersexualidade mais comum, a Hiperplasia da Adrenal Congênita (HAC), destacando os desafios de inserção na educação infantil (EI). É de cunho retrospectivo de análise de narrativas, com base no método qualitativo documental. Retoma dados de uma pesquisa doutoral, que investigou a percepção de profissionais de saúde e de pais sobre bebês nascidos nessa condição. O recorte emerge das narrativas das famílias e os desafios de lidarem com as escolas, a partir da realidade vivenciada. Apresenta o arcabouço jurídico como um dispositivo importante à inclusão, mas as repercussões políticas sociais da conjuntura hegemônica fazem persistir a invisibilidade dessas crianças. Conclui-se que o redesenho da EI para a inclusão efetiva requer ação intersetorial que envolva diferentes atores, sobretudo, as crianças.

**PALAVRAS-CHAVE:** Condição intersexuada. Bebês. Educação infantil. Diversidade. Família.

**RESUMEN:** El artículo tiene como objetivo reflexionar sobre las posibles dificultades enfrentadas por padres de bebés que viven con la condición intersexual más común, la Hiperplasia Suprarrenal Congénita (HAC), destacando los desafíos de integración en la educación infantil (EI). Se trata de un estudio retrospectivo de análisis de narrativas, basado en métodos cualitativos documentales. Retoma datos de una investigación doctoral que indagó la percepción de profesionales de la salud y padres sobre bebés nacidos en esta condición. El enfoque surge de las narrativas de las familias y los desafíos que enfrentan al lidiar con las escuelas, desde su realidad vivida. Presenta el marco legal como una herramienta importante para la inclusión, pero las repercusiones políticas y sociales de la situación predominante hacen persistir la invisibilidad de estos niños. Rediseñar la EI para una inclusión efectiva requiere una acción intersectorial que involucre a diferentes actores, especialmente a los niños.

**PALABRAS CLAVE:** Condición intersexual. Bebés. Educación infantil. Diversidad. Familia.

## Introduction

Early Childhood Education (ECE), the first stage of Basic Education, is fundamentally based on care and education enhanced by interactions and play as the curricular structuring axis, within and for diversity (Brasil, 2009). The child is a socio-historical being with rights central to pedagogical planning, as advocated by legal documents such as the National Curricular Guidelines for Early Childhood Education (Brasil, 2009). Contrary to the principles of care, education, and rights, children with atypical genitalia remain silenced, not only in the school environment but in society as a whole, as is the case with those born with intersex conditions<sup>4</sup>. This silencing occurs especially when a binary sex culture is traditionally established in schools. In this context, children are divided into two groups, male and female, based on their genitalia, leading to binary gender identities: male and female. This division is naturalized and reproduced in everyday school life through practices and discourses that reinforce gender expectations.

However, children with sexual atypicalities do not fit into this gender binarism. They may have genitals that do not correspond to societal expectations of masculinity or femininity. In this context, they are often silenced and prevented from expressing their condition freely and safely, impacting their self-knowledge of their bodies, which is crucial at the beginning of their sexual identity development. Contemporary schools, in their inclusive curricular composition, show a lack of understanding of the world of children living with intersexuality and their families, thus acting in an educational perspective that erases these children and their contexts, as evidenced by the scarcity of research in the field of education on this topic (Deda; Valle, 2021).

The most common cause of intersexuality arises from a genetic condition known as Congenital Adrenal Hyperplasia (CAH). Individuals born with this condition, when their karyotype is 46 XX<sup>5</sup> present: uterus, ovaries, breasts, and virilized external genitalia. Biomedical studies indicate risks of gender dysphoria in cases of high levels of genital

---

4 Human intersexuality refers to an organic condition where, at birth, an individual presents characteristics of both sexes: male and female. In the case of Congenital Adrenal Hyperplasia (CAH), the subject of this study, a 46 XX baby, has a uterus, ovaries, and breasts but produces a higher amount of male hormone. As a result, the external genitalia may resemble male genitalia, although there are no testicles present. The Prader Scale, ranging from one to five, is used to assess the level of virilization, with level five being closer to the male form and level one closer to the female form.

5 From a genetic standpoint, the human species has 23 pairs of chromosomes (46 in total) that determine our characteristics, such as eye color, nose shape, etc. Each pair consists of one X chromosome (inherited from the mother) and one Y or X chromosome (inherited from the father). These chromosomes determine the baby's sex. If the sex is female, the pair is XX, and if male, the pair is XY. In the case of intersex individuals due to CAH, even though they are born with an XX pair, the external genitalia may resemble that of a boy because of increased male hormone levels, causing difficulty in identifying the sex at birth. A karyotype test will determine the genetic sex for sexual designation.

virilization and late diagnosis (Apóstolos, 2017), due to the action of male hormones on the child's brain. Addressing these cases has emerged as a public health issue since CAH was included in the National Neonatal Screening Program (PNTN) in 2012. Ordinance 2,829, which instituted Phase IV of the PNTN, recommended psychiatric follow-up for parents of children with CAH, anticipating the psychic illnesses present in this population due to the sexual dimension dilemmas of the baby.

In a study conducted by Telles-Silveira (2009), the challenges experienced by parents, patients, and healthcare professionals related to the reality of CAH were observed and expressed as follows: "*Fear (unknown disease); anger; denial; sadness; dissociation ('this is madness, how can a child be diagnosed to determine their sex?')*" (Telles-Silveira, 2009, p.115, our translation). According to the author, other feelings also emerged, such as "surprise; paralysis (it's a terrible disease that can lead to death); disbelief (what the mother saw had no connection with what the doctors said); anguish; despair; loneliness" (Telles-Silveira, 2009, p. 115, our translation). Additionally, there were feelings of shame and social withdrawal resulting from the "secret" nature imposed by the situation.

Given the complexity of this situation, CAH requires a comprehensive and longitudinal approach to ensure care and attention from an interdisciplinary perspective, as the issue involves social, subjective, and biomedical dimensions. It is essential to highlight that the importance of intersectorality in public policies has been established since the Federal Constitution of 1988. With the creation of the Unified Health System (SUS), the national health policy, in Article 12 of Federal Law 8.080 (Brasil, 1990a), mandated the implementation of intersectorality by stating: "Intersectoral commissions shall be created at the national level, subordinated to the National Health Council, composed of competent Ministries and agencies and representative entities of civil society" (Brasil, 1990a, p.4, our translation).

In this context, the school, as a space for diversity and human development, plays a fundamental role in promoting various forms of knowledge and guaranteeing rights, including the promotion of physical and mental health. Currently, respect for the diversity of children and their childhoods is, at least legally, a reality. In Brazil, progress made through the Statute of the Child and Adolescent (ECA) - Law 8.069 (Brasil, 1990b), the Law of Guidelines and Bases of National Education (LDB) - Law 9.394 (Brasil, 1996), and more specifically, regarding the curriculum and rights of babies and young children, the National Curricular Guidelines for Early Childhood Education (DCNEI/Brasil, 2009), consolidate the principles of the Federal Constitution (Brasil, 1988). This asserts that children and adolescents are rights holders, and

the responsibility for their care, education, and protection is shared among families, the State, and society.

However, within the context of the legal documents that govern and guide Early Childhood Education (ECE), there is an invisibility of children born intersex, despite advances in the last two decades in the use of terminology related to diversity, gender, and sexuality. In a study on these and other terms such as “sex,” “boy,” and “girl” in municipal documents from Florianópolis and national documents like the DCNEI (Brasil, 2009), Silva (2018) concluded that, unlike the term “diversity” or the binaries “boy/girl,” “man/woman,” the words “sex” and “sexuality” were absent. The author emphasizes the importance of discussing these themes in the normative documents of ECE, as they are fundamental guidelines for constructing democratic pedagogical proposals, “[...] hence the imminent presence of these themes to ensure that practice is inclusive and emancipatory” (Silva, 2018, p. 6, our translation).

Furthermore, there is a considerable lack of knowledge among ECE professionals about this subject, in addition to the absence of public policies that address the needs of babies born intersex. When referring to babies, it is essential to highlight ECE schools, which are formal and collective learning spaces dedicated to the care and education of children from zero to five years old. The difficulties of inclusion and respect for diversity in this initial stage of basic education may be related to sociocultural conceptions based on heteronormative standards, as well as a lack of understanding about this intersex condition. This deepens the invisibility of these children, who continue to face anguish from their parents and are deprived of the social interaction and diversity provided by the school environment. This reality underscores the fragility of the educational system in promoting care and education for these individuals, especially for babies and young children whose integral development is in full expansion.

In this political context, this article is based on data extracted from a doctoral thesis titled “Perception of Parents and healthcare professionals about Children/patients with Congenital Adrenal Hyperplasia and disorder of sex development” (Queiroz, 2018), which investigated the perceptions of healthcare professionals and parents of babies born intersex, diagnosed with CAH, and followed longitudinally in a Neonatal Screening Reference Service (SRTN). Although the educational aspect was not the initial focus of this broader investigation, some concerns and doubts from families were identified and deserved attention.

Therefore, this work aims to examine the potential difficulties faced by parents of children born with CAH and genital atypia when dealing with Early Childhood Education (ECE) institutions, considering the reality of their children. Based on this, the article seeks to

reflect on the challenges faced by parents and babies and/or young children living with the most common intersex condition, Congenital Adrenal Hyperplasia (CAH), especially upon entering the school environment, a significant space for the human development and rights of these children and their families.

A brief explanation of intersexuality in cases of CAH and some approaches adopted over time will be provided. Subsequently, the challenges and progress in the inclusion of children born intersex will be discussed. Emerging issues from parents' statements will be analyzed to understand the difficulties faced by families when dealing with ECE institutions. Finally, we will reflect on the importance of education and an intersectoral approach to advancing toward a society that promotes democratic principles of inclusion and respect for diversity.

### **Historical Overview of Intersexuality: Approaches in the Context of CAH**

Each historical period determined the approach to intersex patients due to changes in conceptions and specific medical techniques of each era. Until the 19th century, the "era of the gonads," the verification of the existence of gonads to specify the child's sex was performed through palpation (Spinola-Castro, 2005). Other elements involved in sex determination, such as genetic, hormonal, and physiological dimensions, began to be considered. During this period, the importance of defining sex was maintained, and elements incompatible with the defined sex were eliminated (Costa, 2005).

Money (1972) conceived the existence of psychosocial neutrality in the initial stage of a child's life, but he suggested that this neutrality would decline after 24 months. In this direction, the sex of rearing gained fundamental importance in determining a person's sex (Money; Ehrhardt, 1972). This perspective was later rejected, and sex determination, from a biomedical perspective, began to encompass biological, social, and psychological aspects. The masculinization of the brain, resulting from the presence of androgens, became valued (Federman, 2004).

The medical-scientific discourse, starting from the Hygienist Reform at the beginning of the last century, focused on the study of diseases and their classifications, categorizing even the different manifestations of sexuality. Consequently, a list of sexual aberrations was established. During this historical period, "pseudo-hermaphroditism," along with homosexuality, emerged as a pathological condition, restricting normality exclusively to heterosexuality (Leite Júnior, 2008). Individuals labeled as "hermaphrodites or pseudo-



hermaphrodites" could be accepted judicially and socially if they chose one of the sexes for life. Sexual aberrations were harshly criticized by Freud (1969) in 1905 in his work "*Os Três Ensaíos sobre a Teoria da Sexualidade*"<sup>6</sup>, as he considered the dispositions understood as aberrations to be aspects of the psycho-affective development of every human being. It is noteworthy that in this historical period, individuals described with etiological conditions now understood as close to intersexuality, and suffering from severe dehydration (as occurs in cases of CAH), often died prematurely. Before this period, in medieval times, cases of intersex individuals were seen as monsters – mixed beings of man/woman – and condemned to the stake (Rocha, 2021).

In recent decades, both Resolution 1664 of the Federal Council of Medicine (CFM, 2003) and the Chicago Consensus (Hughes; Houk; Ahmed; Lee; LWPE1/ESPE2 Consensus Group, 2005) have focused on preserving reproductive possibilities, aiming at the psychosocial adaptation of intersex individuals. These guidelines strive to align, as much as possible, the psychological dimension with the biological sex at all levels: genetic, hormonal, and functional. These guidelines are followed by many healthcare professionals despite the advances recommended by the Swiss National Advisory Commission on Biomedical Ethics in 2012, which produced a document entitled "*Sobre o manejo das diferenças do desenvolvimento sexual – Aspectos éticos relacionados à intersexualidade*"<sup>7</sup>. According to the document, the directive of biomedical treatment should aim at the child's well-being, including psychosocial development and potential surgical procedures, which should be removed from the center of health practices, even considering the persistence of differences in the genitals of these individuals, even after corrective surgery. The term "Disorder of Sex Development (DSD)," used in the medical field to designate individuals born intersex, should be replaced with "differences" or "variations" in sexual development to avoid feelings of shame associated with the previous terminology (Telles-Silveira, 2009).

Only recently, in 2021, did it become possible to register newborns with ambiguous genitalia as "sex ignored." Provision 122/2021 now allows the Civil Registry of intersex individuals to "sex ignored" without the need for judicial authorization or the presentation of medical or psychological exams (Conselho Nacional de Justiça, 2021). Previously, parents opted not to register their babies until the results of the sex designation examination, violating the infant's right to citizenship. According to Butler (2003), there is a social dynamic in which

---

<sup>6</sup> Three Essays on the Theory of Sexuality.

<sup>7</sup> On the Management of Differences in Sexual Development – Ethical Issues Relating to Intersexuality.

individuals who fall outside the heteronormative dimension suffer from silencing and isolation because their bodies do not fit into the categories of male or female. For the author, it is through the response to the question "girl or boy?" that children can situate themselves within the field of humanization in the Western hegemonic tradition (Butler, 2008). What role does education play in this process? We intend to discuss this topic below.

### **Intersexuality, Rights, and Education**

Despite the numerous difficulties faced by this population and their families, some outlined advances have been halted. The proposed law 134/2018, the Statute of Sexual and Gender Diversity (Brasil, 2018, our translation), aimed to uphold the duties and rights related to the LGBT population, but it was shelved. Article 3, Chapter I, stipulated: "It is the duty of the State and society to guarantee everyone the full exercise of citizenship, equality of opportunities, and the right to participation in the community, especially in social, political, economic, business, educational, cultural, and sports activities" (Brasil, 2018, p. 3, our translation).

Article 35, Chapter VII, addressed the prohibition of genital surgery for sexual adjustment in babies and children, unless there were specific health-related reasons (Here, the language of the legal document is recorded, which, depending on the social context, presents semantic and political divergence). The achievements aimed for in the document brought important aspects for this population since, without this legal support at birth, a baby designated as a boy and later redesignated as a girl ends up facing challenges in the legal sphere.

These data, especially the issue of one's given name, would also be significant, as daycare and preschool represent the child's first social environment beyond the family. However, this bill was shelved in 2022.

It is worth noting that in the educational environment, the pronunciation and writing of a name are generally systematized and loaded with meanings related to gender identity, intrinsically linked to the psychic dimension. Thus, the social use of a name, while gender designation or redesignation processes are in place, favors personal recognition, allowing the child to identify with their given name, correlated to the sex they belong to and their history of desires, along with the participation of their parents in this choice. While the law remains unvoted, the resolutions cannot be implemented. When it comes to infants and very young children, these discussions involve the authority and decisions of legal guardians, who often,



when faced with new and complex situations, also experience difficulties and need care and guidance.

The arrangements involving the different dimensions of sexualities must be viewed case by case, making it necessary to consider the various elements involved in this field, among them:

- **Biological sex:** This refers to the characteristics of organisms, being male or female, based on genetic and morphological aspects;

- **Gender:** This relates to behavioral patterns established by society, conceived as being masculine or feminine;

- **Gender identity:** This encompasses how each person identifies, recognizes, and classifies themselves;

- **Sexual orientation:** This pertains to the affective-sexual attraction one person feels toward another, encompassing elements such as fantasies, behaviors, and the attraction itself (Costa, 2005).

Butler (2008) problematizes the difference between gender and sex: since the former is related to the "cultural meanings assumed by the sexed body, it cannot be said that it results from a sex in this or that manner" (Butler, 2008, p. 24, our translation). In this sense, the birth of an intersex baby is experienced differently in each time and culture.

The imaginary surrounding a child with genital atypia can be circumscribed in various ways, once a social inscription is conferred, promoting possibilities of a different bond crucial to mental health at this inaugural time. Early Childhood Education institutions should not only embrace contemporary advances but also disseminate these principles within the community they serve. This involves a comprehensive political-pedagogical project, starting from enrollment, considering issues such as civil registration, social name, and the role constructed from the parent's perspective, as well as the social position in each context and ongoing dialogue with families and the broader school community. These actions can create opportunities for dialogue with families and the community, demystifying a topic that is often suppressed.

## Method

The study is a qualitative, retrospective narrative analysis utilizing the documentary qualitative method in five stages (Queiroz; Pondé, 2020). This method proposes a qualitative analysis structured in five stages, documentary in nature - where the researcher is also the author

of the document under investigation. The first stage precedes the research, involving clinical registration. The second stage involves recalling the contents registered over time, marking the emergence of the researcher's position. The third stage formulates the research question. The fourth stage engages in fluent attention reading of documents, searching for core meanings. The fifth and final stage focuses on the analysis and interpretation of the studied document.

This study followed all necessary ethical procedures in research involving human subjects and was based on documents (medical records) from psychological care provided to patients at the Neonatal Screening Reference Service (SRTN), analyzed retrospectively. It was approved by the Ethics and Research Committee of the *Bahiana* Foundation for the Development of Sciences on August 11, 2016, under protocol number 1,672,790. The initial consultations of patients with Congenital Adrenal Hyperplasia (CAH) at the SRTN, which were the focus of this study, date back to 2014. The data, as per stages four and five of the mentioned method, were analyzed and categorized based on narrative analysis (Queiroz; Pondé, 2020). All confirmed cases of 46XX and CAH up to May 2016 were included, provided they met the following criteria: screening and treatment at the SRTN under study; presentation of genitalia evaluated within Prader stages<sup>8</sup> III, IV, and V; consultation conducted with the psychologist of the multi-professional team comprising the service, as the studied documents are psychological care records; and signature of the Informed Consent Form.

From the electronic records, the following information was highlighted: maternal and paternal perceptions of their babies since the diagnosis of Congenital Adrenal Hyperplasia (CAH); aspects related to parental figures and their interactions with the babies; parents' perceptions of the diagnosis and treatment of CAH and Disorders of Sex Development (DSD); psychologist's impressions of the interventions performed and parental dynamics.

Throughout the study, certain milestones were considered, namely: 1. Diagnostic journey of genital ambiguity and CAH; 2. Pre-surgical period until the karyotype results; 3. Pre-surgical period after the karyotype results; 4. Post-surgical period. To identify the individuals investigated in this study, the letter M was used for mothers, followed by a number (M1, M2, etc.). The same procedure was applied to identify fathers. Children and parents were designated by pseudonyms to ensure anonymity preservation. The material extracted from the records was coded based on emerging categories from parental narratives. Additionally, the psychologist's impressions of the interventions performed and parental dynamics were coded

---

<sup>8</sup> The Prader scale assesses the levels of genital virilization, ranging from I to V, where level I is closest to the female genital format and level V is closest to the male genital format.

in coherence with the method, which involves the documentary study of clinical records, specifically psychological care records. NVivo software was used for data analysis.

## **Results and Discussions**

Out of the thirteen cases studied, all were initially assigned female at birth, and 11 parents opted for genital surgery. It was found that the majority of parents who proceeded with female-assigned surgery believed it would make the child more "normal". It is worth mentioning that by the end of the data collection period in May 2016, eight children had undergone this surgical intervention. Narratives from those who chose not to proceed with surgery at that time cited logistical issues due to unclear service flows (two cases), ongoing consideration of genitoplasty (two cases), and one child awaiting surgery due to health reasons (awaiting a more suitable time for surgical intervention due to microcephaly). It is important to note that the two cases that did not fully embrace the idea of surgery based their decisions on considerations of LGBTQIA+ rights, as recorded in the medical records.

Two distinct phases were identified in parents' experiences with their children: the pre-surgical period and the post-surgical period. The pre-surgical period encompasses events prior to receiving the karyotype results, which biomedically determine the assigned sex as female or male. Post-karyotype data highlight factors that influenced the decision to enroll the child in an educational institution.

Through the review of medical records, it was observed that upon initial revelation of intersexuality and Congenital Adrenal Hyperplasia (CAH) to parents, uncertainty about the child's sex ensued as they awaited test results. This period was marked by suffering, confusion, shattered expectations for the baby, and doubts about how to refer to the child. They found themselves in a deep void, facing depression amid the deconstruction of all the idealizations they had conceived. They searched for signs in the newborn's bodies in hopes of reclaiming part of the dream they had imagined during and before pregnancy (Queiroz, 2018).

It is emphasized that this moment of the newborn's arrival is essential for their psychic formation and for maintaining emotional investments around the baby, who is becoming a subject; it is a crucial moment for building the bond between parents and babies. Preceding this period is the weaving of the phantasmatic and cultural baby, as mentioned by Golse and Bydlowski (2002). In this direction, certain conditions were verified, depending on the dreams parents had woven for their children: A) having a prior dream of having a daughter, being assigned female at birth, and continuing with the assignment until the Neonatal Screening; B)

the initial dream of having been a daughter, being assigned male at birth, suspending the assignment for testing; C) having been desired as a daughter and receiving information that the baby has genital ambiguity at birth, or being informed that the baby's sex is undetermined; D) the parental couple's desire to have a son, the baby being assigned ambiguous sex and registered as male against medical advice. Faced with the confusion encountered, all parents felt the need to forge new perspectives and ideals for their babies.

They adopted the medical perspective of pathology, with the promise of treatment for CAH and surgery as a possibility to 'reconstruct' the genitalia, seeking to alleviate internal conflicts and deal with their emotional wounds. They even envisioned erasing this initial chapter from their baby's history. However, the secret tended to emerge through unavoidable aspects such as the newborn's clothing, the distance between parents and babies, and the initial naming of the baby. There is an imperative of silence about sex, pregnancy, birth, and civil registration during this initial period. There is an experience entrenched in the idea of anomaly, fear of exclusion, and changes in bonds, overshadowed by parental depression. There were formulations of phrases changing the gender of the child and even the name.

This period, crucial for the child's psychological development, is profoundly impacted by genital ambiguity, resulting in the subversion of expectations and understandings. The new body, defined by science, emerges amidst parents' confusion and suffering. What unfolds is the conception of a body diagnosed as diseased by genetic investigation, requiring treatment under the risk of social exclusion, reflecting a lack of belonging due to genital differences.

The confirmation of the baby's genetic sex as 46XX in the karyotype test result elicited varied feelings in parents, depending on whether the baby was initially assigned as a boy or girl and whether they were desired as such. This moment was marked by silence, confusion, and fear:

*My closest neighbors hardly said anything. Only a few asked why I was dressed as a man and then as a woman. S. (the mother) said she was using clothes from the boy who died and was never used (P9 - Margarida's father).*

Before genital surgery, parents adopted a strategy to deal with their baby's genital ambiguity: they kept this fact a secret. In some situations, some family members became aware of the baby's intersex condition but were kept away from the issue presented, as reported by some of the parents.

*(...) People in the 'problem' of people (P1 - father of Jasmine).  
Only my brother, my husband, and I know. (...) (M10 - Mother of Vanilla).*

Regarding the community in which they reside, parents maintained a reserved attitude to avoid disqualifying and embarrassing experiences, as they had previously experienced prejudices and curiosity from fellow villagers:

*Because of thinking badly. Saying it was male-female. (...) Today, due to our posture of staying quiet, we didn't respond to what people said. This silence persists. (...) At first, we thought about leaving. It didn't work out due to job issues (M2 - Mother of Amora).*

In addition to establishing this distance between family and community, parents also brought situations of secrets that touch on the child's life itself, in the sense of not discussing her condition, based on a constant attitude of vigilance regarding her body, leading to delays in toilet training, as the use of diapers served to "shield" the child's body from others' glances and from the child's contact with her genitals. The most drastic measure to maintain parental control over the child was depriving her of attending school.

*I bought a little outfit for my niece, but I didn't give it. I bought it, and I wanted to dress her... Then, I think that, like I did this with her, people will want to do it too (dress the daughter) and I won't allow it." (...) "Her cousin wanted to change her diaper and I didn't let her. Then, she kept insisting and I held J's leg and said, 'NO!'. She stood there scared (...) (M4 - Mother of Orquídea Jequitibá; situation C1)*

*I let her wear diapers. But when she wears underwear, she moves a lot (...) These days, I took off her diaper. She went out naked on the street. (...) It panicked me (...) What if someone talks, someone takes a picture and posts it. Many wicked people (...) (M5 - Mother of Angélica Ariel; situation C2).*

*She's not in school because of her problem... I don't have the courage to put her (...) She asks to go to school (M5 - Mother of Angélica Ariel; situation C3).*

We emphasize the importance of toilet training as a fundamental milestone for children's autonomy and growth (Barbosa; Quadros, 2019). Depriving children of this phase can negatively impact their development, limiting their ability to acquire cognitive, social, physical, and emotional skills. It is a right for infants to experience activities that promote their holistic development, self-awareness, and identity. While the toilet training process is unique to each child, the socio-cultural environment plays a vital role in this journey.

These data bring elements that affect the lives of parents and babies who fear integration into early childhood education or primary school, resulting in reluctance to attend. Often, the school serves as a space that embraces differences and listens, assisting children during this crucial phase and establishing significant partnerships with their families. When families face insecurities, fears, and anxieties, as mentioned in the previous narratives, this can directly

impact children's well-being. Uncertain about how to establish a partnership between school and family, parents chose to keep the child's body hidden and delay the toilet training process, depriving them of social interaction and, importantly, access to daycare or preschool. This attitude reveals a lack of understanding from the family regarding the principles and goals of the pedagogical project adopted by early childhood education schools, weakening the establishment of a trust bond crucial for the education of infants and young children.

The "post-surgical period" comprises parents' views on their children after genital surgery, highlighting aspects such as: reconciliation of 46XX genotype with genital appearance post-genitoplasty; issues related to sexuality; genitoplasty as a secret; persistence of civil registry problems; and persistence of using the male name. Regarding the reconciliation of 46XX genotype with genital appearance post-genitoplasty, two points emerge as crucial in parents' narratives: the relationship of the 46XX genotype - 21-OH with genital appearance after surgery and the possibility of entering a school institution.

The integration of children into school after surgery provided diverse interactions with other children and adults different from their parents. However, narratives reveal that parents only gradually felt capable of disclosing to institution professionals that the child underwent "some" surgical procedure. Before surgery, this possibility was unthinkable for parents, fearing exposure of their children's bodies and, consequently, encountering prejudices, an experience already lived in other social environments. This reflects parents' uncertainty about the educational role of early childhood education in addressing the plurality of identities. Therefore, they did not feel comfortable specifying the type of surgical procedure their daughter underwent.

*I pay for a "mini daycare" to take care of her. On the first day I left her, the woman called me desperate, asking if she had undergone vaginal surgery. I had forgotten to inform her (but did not specify the type of surgery). J. (the baby's father) said, 'She is already traumatized and doesn't like to talk.'*

The mother (M3) continues the narrative:

*Because, when I cleaned her, there was a small spot inside. And anywhere I leave her that doesn't work out.... Now she is in daycare school. So, I already said: she had a minor surgery.*

This illustrates how intersexuality remains a avoided subject. On the other hand, early childhood institutions are not organized to accommodate all children in public facilities, following the field's quality standards (Santos; Ribeiro-Velázquez, 2023), and do not address diversity in all its dimensions. In addition, attention is drawn to the description of daycare only



as a care location, seen as something "non-professionalizing" ("mini daycare" instead of school; the "woman" instead of teacher, etc.), which highlights the persistence of a historically unmet needs-based bias. Despite progress, parents still seem to see EI school as an extension of home. It is worth noting that, according to the National Curriculum Guidelines for Early Childhood Education (Brazil, 2009), EI is considered:

The first stage of Basic Education, offered in Daycares and Preschools, is characterized as non-domestic institutional spaces that constitute public or private educational establishments that educate and care for children from zero to five years old, during the day, on a full or part-time basis, regulated and supervised by the competent educational system authority and subject to social control (Brasil, CNE/CEB, Resolution 05/09, article 5, 2009, our translation).

It should be emphasized that access to quality public EI, secular and socially referenced, should be the right of all babies and young children. It is a formal and collective learning space, a locus of professionalism and inclusiveness requiring higher education teacher training, and continuing education policies as advocated by the LDB (Brasil, 1996).

The study indicated that children who did not undergo surgery had not, at the time the research was completed, entered the school environment. Parents awaited a time when they would have autonomy to take care of themselves, avoiding their condition being noticed by institution professionals.

In the face of the reality of the presence of people with atypical conditions, schools, supported by the government in its federal, state, and municipal spheres, must play the role of inclusion agent, democratizing rights and access for all citizens from an early age. It is necessary to undertake social changes, starting with discussions on a necessary theme. However, in many realities, as portrayed in this study, this condition is still not effectively addressed.

## **Final considerations**

Intersexuality remains invisible in early childhood education institutions and many social circles, as reported by parents of babies. Surgery, seen as an attempt to restore a supposed 'normality', leaves a mark on the body, something many parents claim is a 'forbidden' topic. The history of Intersexuality cannot be 'erased', and it is up to parents to create strategies to deal with the social boundaries they and their babies face. At a time when inclusion and celebration of diversity are proclaimed as ideals, especially in educational institutions, this experience reveals the utopia of equality that was aimed for in the World Declaration on Education for All,

1990, approved in Jomtien (1990), Thailand. Rosemberg (2014) highlights the challenge of breaking the cycle of poverty in Brazil, criticizing the mistaken approach of providing impoverished services to the less fortunate.

Intersexuality subverts social order in that civil registration documents, only recently, included the possibility of registering as "sex unknown". Registering as a girl or as a boy, based on karyotype results, points to submission to the binary condition in which the intersex person cannot fully situate themselves by their own nature. Therefore, it is present in bureaucratic officialdom that resonates in the senses of collective social organization and in the body that lives the difference in subjectivity.

In turn, the school that omits frequent reflections on the issues of diversity in its magnitude not only fails to meet the imminent needs of excluded groups but also helps perpetuate stigmas derived from heteronormativity and fails to create space to address the psychological suffering of parents who find no space to share their concerns.

In this sense, theories and curriculum construction from a collective, critical, and social perspective can be seen as mechanisms for affirming differences, as they contribute to deconstructing hegemonic narratives that delineate the linearity of bodies in school. Among other compositions, bodily ordering excludes and limits the passage of children with intersex conditions, establishing the place of "not being able to be" or "not being able to appear" as the only possibilities for (not) coexisting in school. By including scenarios, perspectives, images of bodies, and groups traditionally marginalized in the curriculum, children with conditions different from hegemonies construct mirrors to exist and be in school. If children with intersex conditions see themselves represented and welcomed in the curriculum, they can feel more included and understood in the time-space of early childhood education.

However, the school alone cannot address these and other plural issues. It is in this sense that intersectionality - health, education, and social assistance - needs to be effectively implemented, aiming at comprehensive care for individuals with intersex conditions, especially babies and young children, when their psyche is still organizing. In other words, including and affirming intersex conditions requires the construction of a complex web of power involving and combining various professionals, families, and institutions. Even though this web reflects a social dimension, the place of the singular child living with an intersex condition must be recognized, protagonized, and narrated by themselves in their different languages, as the experience of those living this reality is the primary source of legitimacy to understand this existence.

Finally, it is important to highlight that after the family, school represents the primary socialization environment for the child, playing a crucial role in their development. Therefore, we emphasize the limitation of the present study regarding the points raised here, the relationship with families, and the challenges of school integration for children with intersex conditions, as it was not the main objective of the broader investigation from which this text derives. However, we observe that the data highlight the recurring anguish and suffering of these mothers and fathers of babies with intersex conditions. There is a need for expansion and deepening of the topic in new research and data that corroborate the emergence and construction of more inclusive public policies. Thus, perhaps it will be possible to minimize the exclusion of intersexuality as part of the reality experienced by individuals attending early childhood education, leading parents to believe that silence is the only viable way to deal with this issue.

## REFERENCES

- APÓSTOLOS, R. A. A. C. dos. **Identidade de gênero, função sexual e qualidade de vida em indivíduos com hiperplasia adrenal congênita e cariótipo 46XX registrados no sexo masculino**. 2017. Dissertação (Mestrado em Medicina e Saúde Humana) – Escola Bahiana de Medicina e Saúde Pública, Salvador, 2017.
- BARBOSA, M. C.; QUADROS, V. As aprendizagens cotidianas: os cuidados pessoais das crianças como gesto curricular. **Em Aberto**, [S. l.], v. 30, n. 100, 18 jun. 2019. DOI: 10.24109/2176-6673.emaberto.30i100.3358. Available at: <http://rbep.inep.gov.br/ojs3/index.php/emaberto/article/view/3213>. Accessed in: 19 Dec. 2023.
- BRASIL. [Constituição (1988)]. **Constituição da República Federativa do Brasil**. Organizado por Cláudio Brandão de Oliveira. Rio de Janeiro: Roma Victor, 2002. 320 p.
- BRASIL. **Lei n. 8.080, de 19 de setembro de 1990**. Dispõe sobre as condições para a promoção, proteção e recuperação da saúde, a organização e o funcionamento dos serviços correspondentes e dá outras providências. Presidência da República; Casa Civil; Subchefia para Assuntos Jurídicos, 1990a. Available at: [https://www.planalto.gov.br/ccivil\\_03/leis/l8080.htm](https://www.planalto.gov.br/ccivil_03/leis/l8080.htm). Accessed in: 19 Dec. 2023.
- BRASIL. **Lei n. 8.069, de 13 de julho de 1990**. Dispõe sobre o Estatuto da Criança e do Adolescente e dá outras providências. Brasília, DF: Presidência da República, 1990b. Available at: [https://www.planalto.gov.br/ccivil\\_03/leis/l8069.htm](https://www.planalto.gov.br/ccivil_03/leis/l8069.htm). Accessed in: 19 Dec. 2023.
- BRASIL. **Lei n. 9.394, de 20 de dezembro de 1996**. Estabelece as diretrizes e bases da educação nacional. Brasília, DF: Presidência da República, 1996. Available at: [https://www.planalto.gov.br/ccivil\\_03/leis/l9394.htm](https://www.planalto.gov.br/ccivil_03/leis/l9394.htm). Accessed in: 19 Dec. 2023.

BRASIL. **Resolução 05/2009**. Dispõe sobre as Diretrizes Curriculares Nacionais para a Educação Infantil. Brasília, DF: Câmara da Educação Básica, 2009. Available at: [https://www.seduc.ro.gov.br/porta/legislacao/RESCNE005\\_2009.pdf](https://www.seduc.ro.gov.br/porta/legislacao/RESCNE005_2009.pdf). Accessed in: 19 Dec. 2023.

BRASIL. **Projeto de Lei do Senado, n. 134, de 2018**. Institui o Estatuto da Diversidade Sexual e de Gênero. Brasília, DF: Senado Federal, 2018. Available at: <https://www25.senado.leg.br/web/atividade/materias/-/materia/132701>. Accessed in: 19 Dec. 2023.

BUTLER, J. **Problemas de gênero: feminismo e subversão da identidade**. Rio de Janeiro: Record, 2003.

BUTLER J. **El gênero em disputa**. El feminismo y la subversión de la identidad. Barcelona: Paidós, 2008.

CFM. Conselho Federal de Medicina. **Resolução CFM n. 1.664, de 12 de maio de 2003**. Dispõe sobre as normas técnicas necessárias para o tratamento de pacientes portadores de anomalias de diferenciação sexual. Brasília, DF: Conselho Federal de Medicina, 2003. Available at: [https://sistemas.cfm.org.br/normas/arquivos/resolucoes/BR/2003/1664\\_2003.pdf](https://sistemas.cfm.org.br/normas/arquivos/resolucoes/BR/2003/1664_2003.pdf). Accessed in: 19 Dec. 2023.

COSTA R. P. da. **Os onze sexos: as múltiplas faces da sexualidade humana**. 4. ed. São Paulo: Kondo Editora, 2005.

DEDA, B.; VALLE, M.M.R. Intersexualidade e sua (in)visibilidade na educação básica. *In: ENALIC*, 8., 2021. **Anais [...]**. Campina Grande: Realize Editora, 2021. Available at: <https://editorarealize.com.br/artigo/visualizar/85410>. Accessed in: 17 Dec. 2023.

FEDERMAN, D. D. Three Facets of Sexual Differentiation. **New England Journal of Medicine**, [S. l.], v. 350, n. 4, p. 323–324, 22 Jan. 2004. DOI: 10.1056/NEJMp038175. Available at: <https://www.nejm.org/doi/full/10.1056/nejmp038175>. Accessed in: 19 Dec. 2023.

FREUD, S. **Três ensaios sobre a teoria da sexualidade**. Rio de Janeiro: Imago, 1969.

GOLSE, B.; BYDLOWSKI, M. Da transparência psíquica à preocupação materna primária: uma via de objetualização. *In: CORRÊA FILHO, L.; CORRÊA GIRADE, M. H.; FRANÇA, P. (org.). Novos olhares sobre a gestação e a criança até 3 anos: saúde perinatal, educação e desenvolvimento do bebê*. Brasília: L.G.E. Editora, 2022. p. 117-130.

HUGHES, I. A.; HOUK, C.; AHMED, S. F.; LEE, P. A. LWPES1/ESPE2 CONSENSUS GROUP. Consensus statement on management of intersex disorders. **Archives of Disease in Childhood**, [S. l.], v. 91, n. 7, p. 554–563, 14 jun. 2005. DOI: 10.1136/2Fadc.2006.098319. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2082839/>. Accessed in: 19 Dec. 2023.

LEITE JUNIOR, J. “**Nossos corpos também mudam**”: sexo, gênero e a invenção das categorias “travesti” e “transexual” no discurso científico. 2008. Tese (Doutorado em Ciências Sociais) – Pontifícia Universidade Católica De São Paulo, São Paulo, 2008.

MONEY, J.; EHRHARDT, A. A. **Man & woman, boy & girl**. Baltimore: The Johns Hopkins University Press, 1972.

NOVAS REGRAS permitem registrar crianças com o sexo ignorado na DNV. **Conselho Nacional de Justiça**, Brasília, DF, 24 ago. 2021. Available at: <https://www.cnj.jus.br/novas-regras-permitem-registrar-criancas-com-o-sexo-ignorado-na-dnv/>. Accessed in: 19 Dec. 2023.

QUEIROZ, I. R. G. de. **Percepção de pais e de profissionais de saúde sobre filhos/pacientes com hiperplasia adrenal congênita e desordem do desenvolvimento sexual**. 2018. Tese (Doutorado em Medicina e Saúde Humana) – Escola Bahiana de Medicina e Saúde Pública, Salvador, 2018.

QUEIROZ, I. R. G. de; PONDÉ, M. P. Pesquisa Documental de Prontuários de Atendimento Psicanalítico de Bebês: Proposta De Análise Qualitativa em Cinco Tempos. **Rev. Investigação Qualitativa em Saúde: Avanços E Desafios**, [S. l.], v. 3, n. 1. p. 1008-1017, 2020. DOI: 10.36367/ntqr.3.2020.1008-1017 Available at: [https://www.researchgate.net/publication/342966085\\_Pesquisa\\_Documental\\_de\\_Prontuarios\\_de\\_Atendimento\\_Psicanalitico\\_de\\_Bebes\\_Proposta\\_de\\_Analise\\_Qualitativa\\_em\\_Cinco\\_Tempos](https://www.researchgate.net/publication/342966085_Pesquisa_Documental_de_Prontuarios_de_Atendimento_Psicanalitico_de_Bebes_Proposta_de_Analise_Qualitativa_em_Cinco_Tempos). Acesso em 26 Jan. 2024.

ROCHA, M. L. B. **Sentidos e significados da intersexualidade na literatura: silenciamentos da vida e da arte**. 2021. Dissertação (Mestrado em Psicologia) – Instituto de Psicologia, Universidade Federal de Alagoas, Maceió, 2021.

ROSEMBERG, F. Políticas públicas de qualidade da Educação Infantil. *In*: SANTOS, M, O, dos; RIBEIRO, M, I, S, (org.). **Educação Infantil**: Os desafios estão postos. E o que estamos fazendo? Salvador: Sooffset, 2014. p. 169-185.

SANTOS, M. O. dos; RIBEIRO-VELÁZQUEZ, S. A qualidade da Educação Infantil que emerge de práticas docentes: uma construção de diferentes autores. **Revista de Educação Pública**, v. 3, v. 32, p. 255–278, Jan./Dec. 2023. DOI: 10.29286/rep.v32ijan/Dec.14605. Available at: <https://periodicoscientificos.ufmt.br/ojs/index.php/educacaopublica/article/view/1460>. Accessed in: 14 Dec. 2023.

SILVA, K. Z. da. Gênero e sexualidade na educação infantil: o que dizem as Dcnei e os documentos da rede municipal de ensino de Florianópolis *In*: SEMINÁRIO CORPO, GÊNERO E SEXUALIDADE, 7., 2018, Rio Grande. **Anais [...]**. Rio Grande: Editora da FURG, 2018. Available at: [https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=2ahUKEwjFptiTt9aDaxUrFLkGHbM3B\\_AQFnoECAkQAQ&url=https%3A%2F%2F7s.eminariorio.furg.br%2Fimages%2Farquivo%2F254.pdf&usq=AOvVaw089lpEJcE-LaWcSzuGJG3F&opi=89978449](https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=2ahUKEwjFptiTt9aDaxUrFLkGHbM3B_AQFnoECAkQAQ&url=https%3A%2F%2F7s.eminariorio.furg.br%2Fimages%2Farquivo%2F254.pdf&usq=AOvVaw089lpEJcE-LaWcSzuGJG3F&opi=89978449). Accessed in: 11 Jan. 2024.

SPINOLA-CASTRO, A. M. A importância dos aspectos éticos e psicológicos na abordagem do intersexo. **Arquivos Brasileiros de Endocrinologia & Metabologia**, [S. l.], v. 49, p. 46–59, 1 fev. 2005. DOI: 10.1590/S0004-27302005000100007. Available at: <https://www.scielo.br/j/abem/a/mGVhXqhtcmJq4CwNMtkX8x/abstract/?lang=pt>. Accessed in: 19 Dec. 2023.

TELLES-SILVEIRA, M. **Hiperplasia Adrenal Congênita**: "Quando o sexo precisa ser diagnosticado": um estudo qualitativo com médicos, pacientes e familiares. 2009. Dissertação (Mestrado em Ciências) – Escola Paulista de Medicina, São Paulo, 2009.

UNESCO. Organização das Nações Unidas para a Educação, a Ciência e a Cultura. **Declaração mundial sobre educação para todos e plano de ação para satisfazer as necessidades básicas de aprendizagem**. Jomtien: UNESCO, 1990.



### ***CRediT Author Statement***

---

- Acknowledgements:** We would like to thank the families and patients followed at SRTN.
  - Funding:** Not applicable.
  - Conflicts of interest:** There are no conflicts of interest.
  - Ethical approval:** The research was submitted and approved by the Ethics and Research Committee of the Bahiana Foundation for the Development of Sciences on August 11, 2016, under protocol number 1 672 790.
  - Data and material availability:** Not applicable.
  - Author's contributions:** First author: field research, data collection, qualitative data analysis and interpretation, manuscript drafting, final manuscript revision. Co-authors: data analysis and interpretation, manuscript writing, final manuscript revision.
- 

**Processing and editing: Editora Ibero-Americana de Educação.**  
Proofreading, formatting, normalization and translation.

