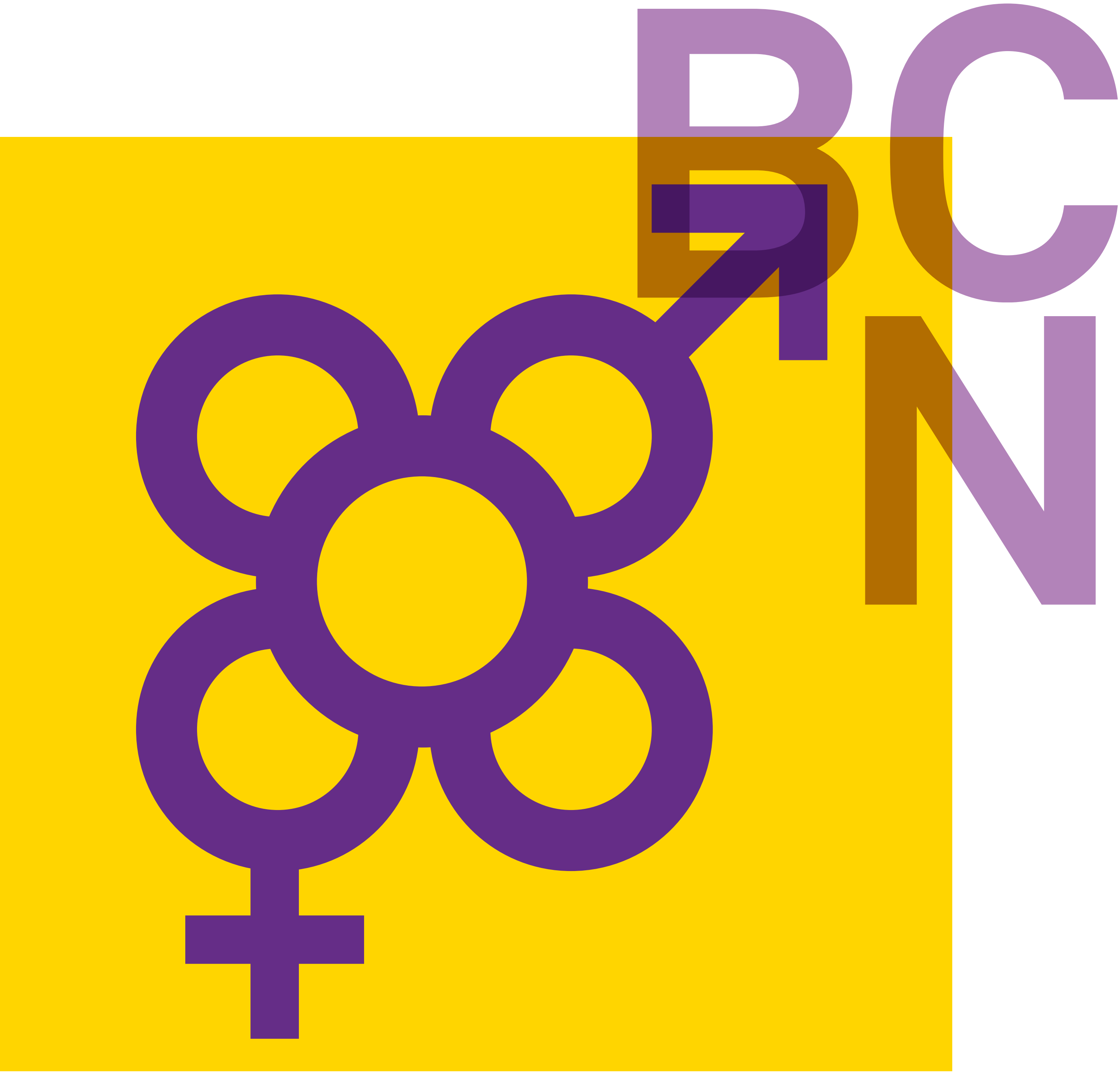
An analysis of the different realities, positions and requirements of the intersex / DSD population (differences of sex development) in Barcelona



Area of Citizen Rights, Participation and Transparency

An analysis of the different realities, positions and requirements of the intersex / DSD population (differences of sex development) in Barcelona

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We would like to thank all of the respondents who were interviewed and shared their knowledge and experiences with us, offering a deeper and more intricate look at the discourses and experiences of the intersex / Differences of Sex Development community.

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CHAPTER I

AN INTRODUCTION TO THIS PRELIMINARY STUDY

What position do people with intersex variations/DSD (differences of sex development) occupy nowadays in the social fabric, in public and healthcare policies, at school and in the media? The response to this question clearly relates to the frequency with which cases of different sex development present themselves within the general population, yet it also relates to the stigma and taboo that accompany people with DSD. The question about frequency arises time and again, and delivers controversial answers. This gives the impression that, in order for it to be valued within a social framework, a fact must be supported by statistical weight. For Gina Wilson, President of Organisation Intersex International (OII) Australia, even the most widespread figure of one case in every two thousand, does this community no favours. According to Wilson, it reinforces the idea that intersex is not a common problem among the general population and that people defined as intersex are a minority, unusual and rare, a product of human variation. Biologist, Anne Fausto-Sterling (2000), is responsible for the other most widely aired statistic. The author estimates the prevalence of intersex at around 1.7%.[i] However, taking into account that this only includes hospital statistics, we could only imagine how much this figure would increase if we were to include all of the people who had never been down the medical route. In fact, the secrecy, decentralised healthcare, lack of patient monitoring and supervision from medical professionals, in addition to, all of the people with differences of sex development who have not been diagnosed or have not attended a medical consultation, means that it is impossible to speak of reliable statistics.

According to the 2014 municipal register of the INE (National Statistics Institute), the population of the municipality of Barcelona amounted to 1,602,386 inhabitants. If we make a estimate, in reference to Fausto-Sterling's more generous statistic, it would mean that the number of people in Barcelona who are intersex or have DSD would equate to 27,240 people. If we use the more modest incidence rate of one case in every two thousand, there would be 801.2 people in the city of Barcelona with intersex variations. But, beyond hypothetical estimates, Barcelona has been and continues to be a city of reference in Spain, due to its long history and experience in caring for people with intersex variations/DSD, both in the medical and associative fields.

We can strive to overcome the unease and discomfort associated with intersex by mapping it out. This requires us to remove and rid ourselves of the fundamental categories and concepts so we can look for those who defend and/or label themselves differently, those who may or may not recognise that they are included in specific categories by professionals and experts in medicine, psychology, sociology, etc. By surveying and mapping out people with intersex/DSD, we can make a wide variety of voices and isolated experiences heard, even those that are conflicting.

Research into intersex variations has called for terminologies and scenarios to be explored that are, for the most part, unknown, and even reject the concept of intersex or the assortment of DSD/SDA (defined as disorders, alterations or differences in sex development). Here, we are talking about groups and people who are identified with specific diagnostic or nosologic labels, such as Klinefelter Syndrome (KS), Turner syndrome (ST), congenital adrenal hyperplasia (CAH), complete androgen insensitivity syndrome (CAIS) partial androgen insensitivity syndrome (PAIS), Mayer-Rokitansky-Kuster-Hauser (MRKH) syndrome, enzymatic deficiencies or gonadal dysgenesis - mixed, complete, or partial Swyer syndrome, (GD), Steroid 5-alpha-reductase deficiency, CAH 17-OH deficiency, micropenis, hypospadias, ovotesticular DSD, mutation of the NR5A1 gene, etc. (medical descriptions of some of these are detailed in the annexed documents).

The network of associations is weak and is usually comprised of patient groups, support or mutual aid groups, the majority operate at a national level (Support Group for Androgen Insensitivity Syndrome and Other Related Syndromes —GrApSIA (as known by its Spanish acronym)—, the Spanish Association of Congenital Adrenal Hyperplasia, Alejandra Grandes Turner Syndrome Association, Klinefelter Syndrome Mutual Aid Group, a.m.a.r. association, etc.). The only association that operates at a regional level is the Catalan Association of Klinefelter Syndrome (http://www.ascatsk.org/) and the AFAPAC association (Association of Relatives and Sufferers of Growth Disorders)[ii], which is registered in Catalonia but attends to people at a national level, and also assists some families and adults with Turner syndrome. In Catalonia, these associations are hosted by two federations: FECAMM (Catalan Federation of Rare diseases) and FEDER (Spanish Federation of Rare Diseases). These groups and institutions play a definitive role in managing the pursuit of support and care, offering information about the most experienced specialists, leading patients to, or informing them about patient referral programmes to multidisciplinary units in other communities, securing finance or funding, promoting social integration, and raising the visibility and awareness of this phenomenon, etc.

Although it will be detailed later in the methodology annex, broadly speaking, the field work carried out is based on:

1. **39 interviews** with key respondents:
    - a) Those who, through their professional activity, offer a diverse vision and broad knowledge on the topic (12 interviewees)
    - b) Representatives of institutions and intermediary bodies for the care of intersex/DSD people (6 interviewees)
    - c) Representatives of Catalan associations (or, in cases where the association for a condition in only in the Spanish State territory, we also interviewed their representatives) (1 mother, 1 father and 1 adult)
    - d) Activists and/or people with intersex/DSD variations from within and outside the associations and support groups in the city of Barcelona (13 interviewees)
    - e) Parents of people with intersex/DSD variations who are active in LGTBI patient associations or support groups in the city of Barcelona (5 interviewees)
2. A **discussion group** comprised of activists, adults and mothers from support groups, and one person who is not involved in any associative network.

The interviews aimed to identify the routes that people predominantly take to search for help, healthcare and assistance, either through the usual medical channels, or via other routes or alternative treatments, within the free public service framework, or through private organisations. Similarly, another aim was to determine public opinion about the level of care received and satisfaction rates, the main obstacles encountered, strategies implemented to overcome these limitations and potential proposals for change, in addition to the legal and social (in)visibility, stigma, discrimination and harassment experienced in social and family life. The following table details the profiles of the people who were interviewed and those who participated in the group discussion, all of whom are from Barcelona, as well as the abbreviations used to refer to them throughout the analysis:

	Abbreviation	Profile
Biomedical professionals (Public healthcare systems and alternative systems)	End.Bog.	Endocrinologist specialised in intersex/DSD in Latin America, residing in BCN
	Cap.Gin.Hosp3	Gynaecologist, head of department, expert in DSD, BCN hospital of reference
	Cap.EndGin.Hosp2	Director of the Gynaecological Endocrinology department, Unit of Endocrine Disorders, BCN hospital of reference
	Cap.EndPed.Hosp1	Director of the Paediatric Endocrinology department, BCN hospital of reference
	Cap.CirPed.Hosp4	Specialist DSD surgeon, BCN hospital of reference
	Sex1	Sexologist, and expert in the LGTBI population in Catalonia
	Gin1	Gynaecologist, and expert in DSD
	Gin.Sex1	Gynaecologist and sexologist, expert in intersex/DSD
	Psych1	Psychologist, expert in intersex and transsexual individuals
	Psych2.Hosp1	Clinical psychologist, expert in DSD, BCN hospital of reference
	Psych.Hosp2	Psychiatrist, expert in transsexuality/DSD, BCN hospital of reference
	Med.Fam1	Family doctor and sexologist, an expert in the LGTBI population

	Abbreviation	Profile
Representatives from federations or collectives	Cap.Hosp1	Medical researcher in DSD, on an international scale
	D-FEDER	Delegates in Catalonia from FEDER
	P-FCMPF	Spokesperson for the Catalan Federation of Rare Diseases
	LGTBI1	Sociologist, expert in transsexuality/intersex issues BCN
	P-Turner2	Spokesperson for the AFAPAC (TS)
	P-ascatsk	Spokesperson for the Ascatsk (KS) association
	P-CAH	Spokesperson for the Spanish CAH Association
	P-Turner1	Spokesperson for the Alejandra Grandes (TS) association
	P-Grap	Spokesperson for the GrApSIA association

	Abbreviation	Profile
Intersex and DSD population (from within the Support Groups and outside)	H-inter	Psychologist, expert on the LGTBI population
	M-Roki	Female adult female, MRKH syndrome, a.m.a.r. association
	P-Roki	Spokesperson for the MRKH syndrome, a.m.a.r. association
	M-Grap1	Adult female, CAIS, GrApSIA association
	M-Grap2	Adult female PAIS, GrApSIA association
	M-Grap3	Adult female CAIS GrApSIA association
	M-Nr5.	Adult female, Nr5a1 gene mutation
	M-Turner1	Adult female Turner, Alejandra Grandes association
	M-Turner2	Adult female Turner, Alejandra Grandes association
	H-Klinefelter	Adult male S. Klinefelter
	H-Hipos	Adult male hypospadias, sexologist and psychologist, expert in intersex issues
	M-CAH	Adult female CAH, Spanish CAH Association
	H-CAH	Adult male CAH, Spanish CAH Association

	Abbreviation	Profile
Parents/relatives of intersex/DSD people (from within the Support Groups and outside)	Pa-Grapsia	Father of a female child with CAIS, GrApSIA association
	Ma-Grapsia	Mother of a female child with PAIS, GrApSIA association
	Ma-ascatsk	Mother from the Ascatsk association
	Ma-Turner	Mother from the Alejandra Grandes association
	Ma-Nr5	Mother from the GrApSIA association

Due to difficulties in arranging interviews with the five social healthcare professionals due to a lack of time or other factors, they requested and/or we proposed that they answer a short **online questionnaire**. Four of them completed the questionnaire (see completed questionnaires in the annexes).

THE OCCURRENCE OF INTERSEX AND DIFFERENT WAYS TO APPROACH IT. IMPOSED AND ENFORCED CATEGORIES

Existing definitions and classifications

Although the term "intersex" has its origins in zoology, specifically in the work of Goldsmith (1917), who spoke of a wide range of sexual ambiguity, Marañón explored it further in his work *The evolution of sex and intersex conditions,* published in 1930. Prior to that, they used the terms "hermaphroditism" or male and female "pseudohermaphroditism" to refer to inconsistencies in sex chromosomes, gonads and genitals. Marañón recognised a stage of undifferentiated sexuality as a starting point for all human beings and introduced the idea of sex as a continuum. The description of gender as a more fluid concept served as a theoretical basis for the definition of the "variances", the "flaws", the "anomalies" or the various "problems" from which sexual differentiation originates and that, in short, give rise to his account of "intersex states". Marañón understood that intersex states include those cases in which physical or functional traits of both sexes coexist in a single individual, whether male or female, these traits can appear in equal or near equal proportions; and, or, more frequently, there is an indisputable dominance of the legitimate sex/gender over the spurious one (Marañón, 1930: 4).

Definitions of intersex, intersexual states or DSD have been updated over the years. Within the medical sphere, intersex has been talked about as the result of errors in foetal development, either in terms of chromosomes, embryological problems or biochemical defects (Piró Biosca, 2002: 129). The consequence of various alterations in the complex physiology that usually results in the normal formation of both the internal and external genitalia (Gracia Bouthelier, 2002: 83), or even among the definitions of DSD: sexual differentiation alterations (SDA). A wide range of pathologies exist, caused by an anomaly in one of the stages of foetal development, which are essential for the normal development of genetic sex (karyotype, chromosomes), the gonadal sex (ovaries or testes) and the internal and/or external genital sex (male or female) (Audi Parera *et al*, 2011: 1).

It is due to theories of the nineteen-fifties from the well-known researcher, John Money, that intersex would become recognised at a scientific level and in the media. Money helped to launch the first standard treatment practices for intersex conditions, with protocols stating that anyone born with atypical genitalia should go through a process of "normalisation" with the help of surgery and hormones, and that this process should be kept secret. This was the standard medical care approach until a few years ago. However, in Spain, and specifically in Barcelona and Catalonia, it would be the surgeon, Joan Martinez-Mora, who played a decisive role in the classification, definition and treatment of these situations. In his 1994 classification, we can observe how conventional nomenclatures were interspersed with classifications that used the specific names of precise syndromes, such as Klinefelter Syndrome or Turner syndrome.

Male pseudohermaphroditism
Karyotype: 46 XY
Gonads: testis
Phenotype: masculine or ambiguous
Ambiguous external genitalia

Female pseudohermaphroditism
Karyotype: 46 XX
Gonads: ovaries
Phenotype: ambiguous feminine
Ambiguous external genitalia

True hermaphroditism
Karyotype: 46 XY or 46XX
Gonads: ovotestis
Phenotype: variable
Ambiguous external genitalia

Asymmetrical gonadal dysgenesis
Karyotype: commonly mosaic
Gonads: testis and gonadal tissue (“streak gonads”)
Phenotype: masculine or ambiguous
Ambiguous external genitalia

Intersexual States. Disorders of Sex Differentiation (Martínez-Mora, 1994: 3) (own translation).

In order to explain what intersex is from a contemporary perspective, we did not find information apart from that proposed by the medical community up to the 1990s. Until then, only medical proposals were regarded as a legitimate form of discourse; common patterns of differences in sexual development could only be explained by gene mutations and "errors in the normal process of sexual differentiation". In the nineties, definitions of intersex started to circulate based on real life experiences. These people formed the first *intersex* activist groups on an international scale, notably the ISNA (*Intersex Society of North America*). One of their first allegations focused on the specific instruction given to patients that they should hide their diagnosis, medical gender reassignment processes, as well as surgical procedures performed. They condemned the secrecy, the shame and the stigma imposed on them, criticised the inherent sexism surrounding surgical decisions, and the surgical model which completely ignored sexuality and the wishes of the people receiving the treatment. This movement built a powerful theoretical device that questioned the deep-rooted and robust social constructions, such as the idea of "normal" based on certain values and gender ideology, as well as the medical and scientific paradigm to "restore" the bodies of people with intersex variations, through surgery and hormones. Their proposal meant, among other things, breaking away from the dichotomy of male-penis/female-vagina, but also challenged "scientific objectivity". As a consequence, science is showcased as a narrative which is burdened by political, religious and cultural values and ideology. This movement pursued the progressive depathologisation and acceptance of intersex bodies as variations within the broad spectrum of human bodies and not as unfinished, impaired or wrong (Kessler, 1998; Chase, 1998, Fausto-Sterling, 2000). The definitions derived from this new, non-pathological perspective of intersex anatomies refer to variations within a wide range of body options: the International Gay and Lesbian Human Rights Commission (IGLHRC) speaks of the “set of variants in masculine or feminine body standards” (IGLHRC, 2005).

In the context of the Spanish State, the drafting of the Law on Gender Identity and Expression and Social Equality and Non-Discrimination of the Community of Madrid, defines it as, the variety of situations in which a person is born with a reproductive or sexual anatomy that does not appear to conform with the typical definitions of masculine and feminine.

In 2006, the *Consensus Statement of Intersex Disorders* (Lee *et al.,* 2006), or the Chicago Consensus, proposed a new term "*Disorders of Sex Development*",[iii] which is well-known by the acronym DSD, which replaced "intersexuality/intersex", and the more antiquated terms, "hermaphroditism" and "pseudohermaphroditism". This change in nomenclature aimed to destigmatise atypical sex differentiations, since it considered the former "terms and labels particularly controversial. These terms are perceived as potentially pejorative by patients, and can be confusing to practitioners and parents alike" (ibid.). The new terminology particularly pleased medical professionals and parents of patients, but also those diagnosed with an intersex condition who did not identify with what was beginning to establish itself as "intersex identity". Nevertheless, this new nomenclature would cause great controversy. Some people with intersex variations/DSD would defend "intersex as their identity even though their original differences had been removed through surgery" and they would reveal "gender re-assignment errors" and errors related to "never being able to identify with the gender imposed".

TABLE 1 Proposal for revised nomenclature

PREVIOUS	REVISED
Intersex	Disorders of sex development (DSD)
Male pseudohermaphroditism Undervirilisation of an XY male Undermasculinisation of an XY male	DSD 46, XY
Female pseudohermaphroditism Overvirilisation of an XX female Masculinisation of an XX female	DSD 46, XX
True hermaphroditism	Ovotesticular DSD
XX male or XX sex reversal	46,XX testicular DSD
XY sex reversal	46,XY complete gonadal dysgenesis

Consensus Statement on Management of Intersex Disorders (Lee *et al.*, 2006) (Own translation).

Recently, the medical community compiled the criticism expressed by activist and patient movements, and is now incorporating depathologised definitions into previous works —in terms of variations and differences—, through the deployment of the acronym DSD as differences of sex development (Audi and Fernandez-Cancio, 2015).

Who does this study address?

To determine the realities, stances and requirements of the people with intersex variations/DSD and their families in the city of Barcelona, we must first recognise this population. Initially, the search for interviewees was based on existing medical classifications defining a spectrum of syndromes that fall within the DSD category in the international Consensus of Lee *et al.* in 2006 —the most recent classification used by the international medical community and expert professionals in the city of Barcelona—:

TABLE 2 Examples of DSD classification

Sex chromosome	46, XY DSD	46, XX DSD
45,X Turner syndrome and variants	Disorders of gonadal (testicular) development (1) complete gonadal dysgenesis (Swyer syndrome); (2) partial gonadal dysgenesis; (3) gonadal regression; and (4) ovotesticular DSD	Disorders of gonadal (ovarian) development (1) ovotesticular DSD; (2) Testicular DSD (e.g. SRY+, dup SOX9); and (3) gonadal dysgenesis
47, XXY (Klinefelter syndrome and variants)	Disorders in androgen synthesis or action: (1) androgen biosynthesis defect (e.g. 17-Hydroxysteroid dehydrogenase deficiency, 5α-reductase-deficiency or mutation); (2) defect in androgen action (e.g. CAIS, PAIS); (3) LH receptor defects (e.g. Leydig cell hypoplasia); and (4) disorders of AMH and AMH receptor (persistent müllerian duct syndrome)	Androgen excess: (1) foetal (e.g. 21- or 11.-hydroxylase deficiency); (2) fetoplacental (aromatase deficiency, POR [cytochrome P450 oxidoreductase]); and (3) maternal (luteoma, exogenous, etc.)
45,X/46,XY (mixed gonadal dysgenesis, ovotesticular DSD)		Other (e.g. Cloacalextrophy, vaginal atresia, MURCS [müllerian duct aplasia; renal aplasia, and cervicothoracic somite dysplasia], other syndromes)
46,XX/46,XY (chimeric, ovotesticular DSD)		

While consideration of karyotype is useful for classification, unnecessary reference to karyotype should be avoided; ideally, a system based on descriptive terms (for example, androgen insensitivity syndrome) should be used wherever possible. StAR refers to the steroidogenic acute regulatory protein.

Consensus Statement on Management of Intersex Disorders (Lee *et al.*, 2006) (Own translation).

However, after contacting people with these variations, both within and outside of the associations, it was found that these people were rarely recognised under the intersex/DSD umbrella in any of its forms (such as anomalies, disorders or differences). Rather, these people more frequently identify themselves with characteristics of their own syndrome and make specific demands for their own conditions, without establishing connections with other intersex variations/DSD. A key point during the research interviews was when respondents were asked if they considered it appropriate or helpful during the planning of procedures or public policies, to use this umbrella term, whether it be intersex, DSD or another. The responses varied widely among interviewees. H-Hipos noted:

> Depending on who I talked to during my life, many people within the group of people with hypospadias, told me: "Yes, I am" intersex, and others said to me: "No, not at all". So, clearly... What they have in common is difference, there is variation, whether you like it or not: physiological, biological, chromosomal or hormonal. There is variation with regards to what is normal, what is most common, what is normal in quote marks, and we always talk about what we have in common. Always. Bodies are always defined by "it's like this or like that", "a boy is like this, a girl is like that". There is so much diversity between the binary notions of female and male. But, it is important to find common ground to talk about the same experiences; it is a way of depathologising too, because you get to know people's life experiences —it's important—,to know a little bit about how we have lived, because, from what I have experienced, there must be thousands of us. At the beginning, I thought I was alone. But in the end, my needs as a man with hypospadias are very similar to those of many other men. Socially, we've had the same fears, the same feeling of being different, the same secret that we've had to keep for our entire lives and which some are still holding on to. So, that is how it is, it is important to raise awareness about ways to not pathologise our condition. And to give people the option of having resources like this.

As for Cap.EndPed.Hosp1, bringing together all of these conditions under the same umbrella only makes sense in the scope of medicine or treatment. For example, when specifying diagnostics, protocols, medical initiatives or multidisciplinary care requests with psychologists, etc. As for professionals, it does not make sense to do it from an associative or social perspective, because each group has very specific problems and many of them are not interrelated. Cap.EndPed.Hosp1 gave the example of Turner or Klinefelter syndrome, which require solutions to problems that differ greatly from other types of DSD, ranging from fertility, to specific issues related to learning and cognitive, intellectual and neuropsychological profiles.

As for Cap.EndGin.Hosp2, it is important that appropriate distinctions are made in the search for an umbrella classification. For professionals, it is necessary to distinguish between differences of sex development, which include MRKH syndrome and different intersex conditions, where there is a "discordance" between the chromosomal gender and the genital and/or phenotypic sex. Under this definition, MRKH syndrome would not be considered as a form of intersex, because the chromosomal gender is XX and the normal female phenotype is present (however, menstruation is absent due to the underdevelopment or absence of a uterus and vagina).

> Although MRKH is a congenital vaginal agenesis anomaly, it does present a normal karyotype. / /[iv] It is therefore considered as a developmental anomaly, but not as an intersex state, which is something different. Many intersex states present congenital vaginal agenesis, yet not all types of congenital vaginal agenesis give rise to an intersex state. Intersex states include hermaphrodites and pseudo-hermaphrodites: hermaphrodites have a mix of ovarian and testicular gonadal tissue (this could mean one ovotestis, or one testis and one ovary…: they have two gonads), and pseudo-hermaphrodites have only one type of gonadal tissue, but their sexual characteristics conform to those of the other sex; a karyotype 44, XY male, with or without testes, develops in the way a female would, whilst a karyotype 46,XX, with ovaries, would develop like a male. These are intersex states. The MRKH karyotype is always 46XX and patients develop as women and have a congenital agenesis of the vagina. Therefore, it is not considered as an intersex state, but as a developmental anomaly (Cap.EndGin.Hosp2).

People consulted outside of the support groups were rarely aware of the connections between the different syndromes, or understood the common struggles shared between them. Of the groups consulted, only GrApSIA could name other syndromes and some of the connections between them. This is not only the result of chance. This group of people with intersex variations/DSD receive the most media exposure and garner more health and social involvement, due to the fact that it participates in research, publications and medical meetings regarding DSD throughout Europe.[v]

Despite the lack of knowledge or disidentification from the start, we were able to identify common causes of problems expressed by the interviewees with different intersex variations/ DSD (in essence, these were about the care model and the models related to the devaluation of masculinity and femininity). In this way, by always keeping the creation of health and social policies in sight, we agree to overcome the act of classification itself, as well as the limitations that their definitions entail, and to include people in the sample whose problems and needs are connected to the sexual/reproductive anatomy of a community that does not fall within the socially expected margins. Thus, for example, regardless of whether MRKH syndrome falls within the DSD classification of 2006, many women with MRKH syndrome and AIS found help and meaning when they shared and connected their experiences. In the same way, some women from the GrApSIA association said that, in the past, connections between intersex and transsexuality were rejected, and since they overcame the prejudices facing this group, they have found significant similarities in their experiences, which has helped them to understand themselves better and accept who they are. The truth is that this lack of knowledge on the part of our interviewees about other intersex variations, aside from their own, has made it much more difficult to explore synergies. The people who have gotten to know and have connected their experiences with other groups argue that it makes sense to find common struggles and needs, and to join forces when proposing initiatives or policies, without forgetting or forsaking the needs or specific demands of each condition.

THE INTERSEX/DSD COMMUNITY AND THEIR INCLUSION IN LGTB POLICIES: WHETHER OR NOT IT BELONGS IN THE LGTB(I) GROUP

A report published in 2009 by Barcelona City Council assessing the reality of the LGBT community within the city of Barcelona, speaks of a highly divided group with unclear perimeters; how the letters that make up the acronym are inclusive or exclusive: the “B” for “bisexual” disappears, the “T” for “trans” is forgotten, add the “Q” for “queer”, include the “I” for “intersex”, or the “G” for “gay” takes centre stage and even covers up the “L” for “lesbian”. The contributors spoke of internal conflict related to being part of the group, and their sense of belonging or rejection in relation to the categories. They also explained the inability to talk about a cohesive group, “because gays and lesbians have no relation to each other, and the vast majority of lesbians and gays have no contact with anyone who is *trans*» (Coll-Planas i Missé, 2009). The contributors concluded that the labels are not readily accepted by the people that they intend to group together. Nowadays, the inclusion of intersex in the acronym is the most poorly received by the people it is intended to represent.

Many people from the LGTB community, including some medical professionals, consider intersex as something which is always related to unusual genitalia. However, as we have seen in the comprehensive list of conditions set forth under the DSD heading, many bear no relation to atypical genitalia, and the majority of these people do not identify themselves as “intersex” either. It is difficult to speak of the existence of an "intersex” community, not only because of the divergent and contradictory definitions of intersex and the disidentification with the term, but also because of the fact that we are not speaking of identities themselves, but a physiological state linked to hormones, chromosomes, genes, gonads, genitals, etc.

The issue is that, within the community of intersex people, there is a great deal of diversity. There are many people who only perceive their situation in terms of their anatomy, the function of their sexual organs, the possibility of having normal sexual relations or if they need a procedure in order to have intercourse, etc. Then, you come across another group that views intersex more from the perspective of gender identity. These groups are much closer to LGTB groups than the rest. In addition, the rest, the majority, are heterosexual, cissexual, regardless of how their genitals are.

> Therefore, talking to them about gender identity or sexual orientation, is like another world for them, a world that they do not feel connected to. They don’t believe that it has anything to do with their own story. And of course, you say: “I don't know, somehow they want to insert me into something that is not part of my story”. // Of course, there is a relationship between the two. Butler made a very interesting observation when he proposed *queer* theory and starts by saying that the sex-gender dichotomy really is just an invented dichotomy, and considers intersex as an example of the fact that this dichotomy exists even in nature. But, after a series of practical diversions, you are lead to the fact that there are people who feel that they have been included in certain discourses with which they do not identify at all. Of course, if you cannot identify with a group, you will not participate in it. For example, I participate in the LGTBI organisation because I am gay. If I were heterosexual, I wouldn’t participate. I have my connection. And when I’m in the LGTB world, as a gay man, as a homosexual… The “I” is not a part of that for me. But of course, what happens? In addition to that, I had a natural gender transition when I reached puberty. Likewise, my experience was almost the same, in the sense of realising that your sexual identity does not match the gender that was assigned to you, it’s very much like that of a transsexual person. And in fact, I speak with trans guys and we share a lot of the same experiences. Even about how to get changed at the gym without anyone noticing. It’s the first thing that anyone asks me: “How do you view yourself, what was your childhood like, how was it?”. Everything. Everything, right? The excitement of seeing the first hair. Of course, I, as a homosexual, and for having experienced gender transition, have a lot in common with the LGTB community. But I am an exception. The freak among the freaks. [Laughs] / The majority of *intersex* people have nothing to do with all of that (H-inter).

In the same way that Coll-Planas and Missé (2009) diagnosed the LGTB population, we have repeated the same process for people with intersex variations or DSD. Not only does the use of categories create conflict, with respect to the definition of the intersex state itself, but also with regard to the inclusion of the “I” within the LGTB acronym. First of all, it gives the impression that they have been made to fit in with a shoehorn. M-Grap3 expressed that:

> I’m still unable to see the “I” in here, just because these are people that have problems associated with a related issue. When he explained it [a trans man at a conference], it seemed to me that the same thing happened with trans people; that they were included without them asking [for it]. In many places, they included the “T” without them asking [for it]. It’s almost the same situation today. We are [emphasis] the “I” and nobody has asked us anything, and people put the “I” on the end of the word, but: “do you know what you’re talking about, “simpleton”? What is this here? Tell me, why have you put me here? They don’t know why either (Discussion group).

With any mention of the LGTBI organisation, the response is to request a clarification about the gap and differences between LGTB and what the "I" actually means. In a rather indignant manner, H-Klinefelter recalled a film that premiered recently, *The Danish Girl* (2015) and which, in his opinion, clearly showed in some scenes that she was intersex because she was infertile and had phenotypic traits. However, not only did they not pay attention to this, but all of the film critics and viewers mistakenly labelled her as a transsexual. “She’s not transsexual, she’s intersex”. It draws our attention to how these categories are seen as being mutually exclusive, when we are talking about different issues, about anatomies —intersex—; about identity —transsexuals—; about sexual orientations —gay, lesbian, bisexual—, or about gender expression. Therefore, a person with an intersex variation just like anyone else, could be cissexual, or also transsexual, in the same way that they could be heterosexual or lesbian/gay/bisexual.

We’ve said that, among the DSD population and their relatives, there’s a lack of knowledge about other intersex variations/DSD, and about other groups. They don’t envisage sharing problems, needs and complaints, and there is ignorance and/or rejection in response to these all-encompassing terms. For this reason, it would be very difficult to compile all of the needs of such a diverse community that can barely recognise themselves using the categories that supposedly,—in theory— encompass them. On the other hand, there is no particular social group, association or political organisation like LGTBI that people with intersex variations or their parents can participate in, except in isolated cases such as, in the Lambda de Valencia organisation or AMPGIL (Association of Parents of Gays, Lesbians, Bisexuals and Transsexuals). With regard to the LGTB collective, Coll-Planas i Missé (2009) took the view that, despite recognising that the collective is very divided and that grouping them all together under a single term is a falsehood, a social construct which does not fully address their daily reality, it is useful in strategic terms. Perhaps we should think about intersex as part of the LGTBI acronym in the following way:

> This is about a falsehood which has turned out to be advantageous in unifying people and combating the oppression experienced by people whose gender identity does not correspond to their bodies, by people who do not feel attracted to the opposite sex or whose bodies cannot simply be labelled as either male or female. However, we believe that the use of this construction must respect the diversity that exists within the group and that, following the approach of strategic essentialism (Fuss, 1999) on employing identity labels to fight oppression, we must not forget that this is about constructions and they do not respond to the essential or unchangeable characteristics of the people that they group together (Coll-Planas and Missé, 2009).

The logic behind including the "I" in LGTB is not so absurd if we focus on social change. Modern feminists, organisations, *queer* and LGBT groups and activists embraced the "intersex cause" as a source of inspiration and liberation in response to the "heterosexual matrix" which Butler made reference to, in other words, elements which presuppose the need/obligation to assume only one biological sex which is consistent with gender identity and roles, and which in turn, generates heterosexual desire. Let's say that the same cultural devices and the same historical matrix that stigmatise, discriminate against and violate lesbian, gay and bisexual people, are also those that have the same impact on intersex people. Society only accepts binary complementary genders —male-female—, which have a life-long unique and stable identity, and are heterosexual and able to reproduce. To all of this we have to add the assumption that leads people to think thatpeople with mixed-sex biologies will also have unstable gender identities, and a high rate of homosexuality and transsexualism due to the hormones that their brains have been exposed to. On this assumption, Cap.Hosp1 stated that in order to provide adequate psycho-social care to people with DSD, it's important "in principle, not to place everyone under the LGTBI label. Parents, in particular, may see this negatively, in the sense that it conveys that there may be doubts about gender identity. / / Even though later on it may be linked to LGTB". With regard to the connections between transsexualism and intersex conditions, it is common for people with intersex variations/DSD to go from rejecting or being indifferent about transsexualism, to finding connections with it that even offer meaning and support:

> I didn't understand it before, but when I got the opportunity to speak with trans people, I began to understand it. Because it's not the same and yet, it is the same. Of course, when you go to the doctor and he tells you: "You should have been a guy", he's questioning your identity. And this is where everything connects, in other words, with everything that is related to the pressures of masculinity, femininity, of what it means to be a man… (M-Grap2).
>
> M-Grap1: It took me a while to realize that, for a person who changes gender, ultimately what he feels is a discordance between the inside and out. You do not know to what extent he has learned how he should be. Perhaps you don't need to. This should be what is deemed normal, to be able to have a woman with a penis or not. And it's here that I see the connection. They force you to choose one box or the other. And what happens to us is the same, but the other way around: you were in the box and suddenly you've been removed from it. They tell you: "The thing is, you shouldn't really be in that box, you have something different".
>
> M-Grap3: Or, it's worse than that. In other words, in our case it is: "You don't fit into any box, but we can fool everyone". Or, in other cases it is: "I will let you change boxes, but you have to change box" "I will let you change boxes, but you have to do as I tell you so you won't be like…" Of course, many times, there are people who want it to be like that. But, clearly, they want to do it like that because they don't know any other way. Because the system forces you to change boxes in a specific way and many people don't understand or know that there are other options. If people took another look around, many would not have undergone surgery. What's the need for it? (Discussion group).

As for Psych-Hosp2, it only makes sense to apply LGTB social policies or gender policies to intersex in cases that exhibit comorbidity, in other words, when differences of sex development are intertwined with an LGTB experience. "Only this community would have received the LGTBI label". When people were informed about this study and heard the acronym LGTBI, many people claimed they "have nothing to do with it". The truth is that very few intersex people have explored LGTB organisations to legitimise their lives and address their own needs. The majority feel represented by the discourse around genetic anomalies or variations and gender theories are foreign to their lives. While LGTB organisations call for human and sexual rights, those in the associations and support groups demand medical and healthcare rights (health activism). In short, with regard to the legislation and intersex policies generated through LGTBI activism, there is a perceived need for training/information on the different intersex variations/DSD, in order to tackle the specific needs of each community in suitable ways.

> The resistance I encounter in the "I" group is that there are those who think that having intersex genitalia or *intersex* morphology implies an intermediate gender, you do not feel like a man nor woman and things like that. It's not a rejection, it's not "I don't want to identify myself that way", rather "I don't want anyone to be confused by me, I prefer for them to know me as I am" and "I don't define myself like that, but in another way". It's a more relaxed type of discourse, isn't it? / In addition to this, each time a law is passed, if the legislation is relevant and meets a real pre-existing need, and not an invented one, this is very good. Because it brings a new reality to the table, a reality that we need to be talking about. Then, when a baby is born, or a person goes to the doctor because they haven't started their periods and they discover that they have AIS, and it's diagnosed, then they already have a reference, and they know that there's a law or something, and that explains to them what is happening, and what they can expect. // But, it's also very necessary that medical professionals, psychologists and others know about this reality and have a reference framework. With the *Consensus* I thought, "good, it's being talked about, everyone has been involved", but that wasn't the case, there is absolute ignorance there. And look, it's all pretty clear: "Unnecessary procedures, what a joke". "We must maintain sensitivity." "The functionality of the baby when it's an adult as well as its future health and quality of life are very important." "There is no evidence that parents love their children more if they have normal genitals or not". This kind of thing. But no, they have no idea (H-inter).

THE MAIN PROBLEMS AND NEEDS OF THE PARTIES INVOLVED

From people with intersex variations or DSD:

For many people diagnosed with intersex/DSD, the experience is entwined with health issues, stigma and secrecy, silence and/or solitude, with secrets that have been imposed or agreed to, and lies. The secrecy, rejection and social invisibility with regard to their intersex/DSD is one of the most widespread problems among the people interviewed. This translates into difficulties in social interaction, or even into situations of abuse, which can have serious consequences on self-esteem and self-image. Add to that poor medical experiences, uncertainty in response to diagnoses and treatments, and the iatrogenic effects of treatments and surgery, and not forgetting the health problems associated with certain conditions. While we are unable to go into detail about each one of these problems, here are some key notes.

What are the main problems reported by people with intersex variations/DSD and their families?

Negative MEDICAL EXPERIENCES

Uncertainty

Medical pilgrimage

SOCIAL INTERATION (rejection, harassment, bullying, etc.)

SECRETS, LIES AND SILENCE

HEALTH PROBLEMS

Loving relationships

Sexuality

SELF-ESTEEM SELF-IMAGE

Devaluation of femininity/masculinity

| STIGMA |

ANXIETY | ANGUISH | BLAME | SHAME

FEAR | LONELINESS | ISOLATION | UNCERTAINTY

Health problems and difficulties in care

Something that both professionals and patients with intersex variations/DSD insist on is the need to educate the population about the diversity of conditions under this umbrella. The stereotypical views that circulate about intersex people are about ambiguous genitalia and issues that affect the sexual and reproductive anatomy, failing to recognise the health problems faced by these people. This is particularly true for those with TS, CAH or KS, which require almost immediate healthcare. They also insist on the need to avoid lumping together everyone who suffers from the same condition, "as there are varying degrees": "I have been very lucky, because the degree to which I'm affected is low. It only affects my height and I'm a little underdeveloped, but there are others who have problems with their hearts, thyroid, vision..." (M-Turner1). In this case, the types of problems that are present and the requirements are similar to other illnesses covered under the FEDER umbrella.

There are limitations when it comes to receiving adequate, comprehensive, and free healthcare which makes patients into medical pilgrims. On many occasions, accessing adequate biopsychosocial care is linked to the patients' buying power, and economic status. There are many reports of dissatisfaction and a lot of money spent on private medical insurance and second opinions from other specialists. H-CAH is unable to hide her desperation: They talk about changing the treatment plan each time you visit a new specialist, "although I carried a medical report which said that under no circumstances should I change pills". Since she was prescribed dexamethasone she has been experiencing dizziness, fatigue, malaise, tachycardia, insomnia, mood swings and even "an epileptic seizure". She has lost her job and suffers with anxiety. When she told the doctors about these symptoms, they changed the medication again or prescribed her with anti-anxiety medications. Her desperation drove her to see private endocrinologists that she found over the Internet, private centres where they would perform an MRI to see how her adrenal glands were working. Someone said that they were ageing and that she should have an operation. The reality is that the testimonies swing between this despair, permanent uncertainty and the overwhelming urge to be accepted into a specialist centre, such as the Metabolic Disorders Unit at the Hospital Clínic, a centre that does not fall within her catchment area for medical care.

Another complaint highlights the chronic prescription of medication, ongoing changes to active pharmaceutical ingredients, brand names (some medications are no longer manufactured) and dosage adjustments. They talk of the need to find specific pharmacies that can prepare the exact composition of some medications; of having to collect the medication in the pharmacy of the hospital of reference, being unable to take the prescription to any pharmacy, then having the additional obstacles associated with living outside the city or in rural areas; and, above all, of the high cost of medications that are either not covered by social security or are waiting for the medical boards to approve their coverage.

For example, when interviewees with TS report health problems, the first things they mention are short stature and delayed sexual development, their own specific physical features, the absence of menstruation, incurable sterility, heart or kidney problems (horseshoe kidney), high blood pressure, obesity, diabetes mellitus, cataracts, thyroid problems, arthritis, hearing problems and learning difficulties , especially in mathematics, or other tasks, such as reading maps or visual organization. As for KS, the same attention deficit problems are reiterated, alongside difficulties in language development, learning words, reading, writing and spelling. With regard to CAH, the main and most serious issue that came up during the interviews was salt-wasting syndrome, which occurs in newborns. it is a complication that, if left undetected, can quickly result in death. It also requires life-long monitoring to adjust the dosage of glucocorticoids in response to sickness, injury or stressful situations —“stress dosages”—. Women with CAH also have problems with atypical genitals such as the vagina, clitoris or labium. Women with AIS or Swyer syndrome only mentioned physical health complications arising from medical-technological procedures —iatrogenics, cause by HRT or surgery—, oesteoporosis, the absence of a vagina, as well as atypical genitals inherent in PAIS. And, women with MRKH only pointed out the absence of a vagina.

In the social sphere

When the appearance of the external body is non-normative in terms of gender —body forms, fat deposits, facial or body hair in women, breasts in men, etc.— patients report various forms of harassment, discrimination or even abuse in social interaction, especially at school:

> I always received some incredible beatings. Not physically, of course; psychologically. And to top it off, they bullied me at school because of the moustache, hyperplasia, etc., and from then on, just because they wanted to. The labelled me a he-she. But hey. Then, they wanted me to play basketball and football with them. They can go screw themselves. Yes, I was good at basketball. And it interested me, I like to be with the guys because I didn’t want to be with the popular girls screaming like a pop fan. I enjoyed playing basketball. Not because I was a lesbian. There are thousands of straight girls that play basketball. I don't have any other explanation: it's just that people are assholes from a young age. There's no other way to describe them. When I left school, I didn’t want to go back there ever again. // So, when someone tells me that they have been bullied, I can't handle it (M-CAH).

On the other hand, the lack of information about different intersex variations from the institutions places people in helpless situations, at a disadvantage and completely vulnerable before the Administration:

> The other day, I was left astounded when [the president of the CAH association] told me that there had been cases of people with the same condition as mine that had gone to get their driving license and had been

> told that they wouldn't be able to drive the car. They put obstacles in the way to stop you getting your driving license. I said: But what does it have to do with that? (H-CAH).

In the intimate and personal sphere

The experience of being ashamed of oneself is created and recreated in the recounting of personal stories, in every little secret kept within the family, or in every social scenario in which they feel the need to hide. A cycle of interrogation emerges, the fact of "being questioned" and "questioning oneself" regarding the body, gender identity or desire. Being biologically different in terms of anatomical and/or reproductive sex —both *visibly* (the appearance of the external genitalia and phenotype, fat deposits and hair distribution, muscle development and general external appearance), and *invisibly* (chromosomes, gonads, internal structures)— leads us to think that this biological divergence will influence their identities and life expectations and desires:

> I...even when I was little, you are aware of what you are thinking... Well, I don't think this is something that happens to everyone. But I thought that maybe I should say that I'm a lesbian because I couldn't imagine being with a man, not even now. I just can't. Not me. Then, later, as you grow up, you realise that it is not for this reason, but you have come to think of it like that. Because of course, that is why you have to get to know yourself. I think that I could fall in love with a woman, but not with her body. It's always like that, about sex (M-Nr5).

At the same time, the need to be able to accept one's own body or differences is recognised:

> To accept oneself even more. To feel like a woman. It is what you need. It's the fact of knowing what it feels like in normal circumstances to have intercourse. There are many ways of acting like a woman, and I'm capable of very few of them. And the lack of confidence that builds up inside you really knocks you back. I have hardly any confidence in myself (M-CAH).

In this sense, sexuality and relationships with a partner are one of the most widespread fears:

> The first time, you know, when you're with your partner, it's very scary. Afterwards you're fine, but you're fine because you accept it, because you know that there are girls with hyperplasia, and even normal girls whose flow is not thick, it's more like water. So, you have to keep dilating it over and over again. It makes me mad, I get mad. I mean, I'm upset because the other person has to be doing this all the time. In the end it's all unnatural. It really bothers me that I have to use external objects. They're not a part of me. They do something unnatural to me. And, why, if I am a woman? A lot of people have said to me: "You're making yourself the victim". Well, no, I'm not making myself the victim. It's how I feel. It's as if we were told: "You are a woman, but you're not", when it comes to sex, because of the way your vagina and clitoris are... On the inside you're freaking great, but on the outside you're not (M-CAH).
>
> Perhaps you want to meet someone, or maybe not: to go to a bar, meet a girl, have sex with her and then go home, I can't do this kind of thing because of the way I am. Because of the

> way I feel and my body. I know that I shouldn't be so fearful, but I don't want to shout it from the rooftops. Why not, right? It's very messed up. It's not like saying "I was a drug addict" o "I had anorexia", which is already messed up on its own. In addition to the beating you get from society, they put a lot of crap in your head. // It's the crap from society that's in here, especially from Telecinco. I say, OK, I'm going to my room to watch some TV shows and films. Afterwards, I've always been, if I have a partner, been with my partner and I almost forget my friends. Perhaps it's for the fear of losing that person and having to go back to the start of the cycle (M-CAH).

The concept of "fear of devaluation" is especially useful in analysing the experience of women with intersex variations/DSD, because it is connected to their level of adaptation and perception of having a compromised womanhood. Depending on one's own subjectivity, of the context, but especially on one's own gender expectations, these women feel more fear of rejection and of not being valued and cherished by family, friends and, especially, by their partners. This fear is related to a kind of "functional inability"; in other words, not being able engage in heterosexual intercourse — with a vagina that is adequate for penile intercourse— or not being able to get pregnant. These limitations are particularly challenging for those who want to get married and have a traditional family —to experience the joy of pregnancy, the sense of belonging and recognition bestowed by blood ties, etc. In many women with CAH, TS, MRKH syndrome, AIS or Swyer syndrome, this fear of devaluation is apparent.

But in truth, we discover important nuances when we analyse the "devaluation of femininity" in women with different types of intersex/DSD. In all of these cases, menstruation can not occur naturally, nor fertility without medical intervention (see annexes). Similarly, it is possible for women with CAH to have regular menstrual cycles and even come to experience pregnancy, through HRT, as well as in cases of Swyer syndrome (via embryo donation to their own uterus), and in TS. We observe how each one of these conditions is related in diverse ways to the traits that give rise to female identity: chromosomes, gonads, genitals, external appearance, menstruation, fertility, pregnancy. With respect to the differences between the expectations of womanhood for women with TS and others, M-Turner1 said:

> Perhaps physically, you notice that you are different from other women. You consider yourself strange. Later on..., in my case, I would like, perhaps, to have surgery. // Aesthetically, whether you want to or not, obviously, you look at your physical body and you're not happy with what you see. // The chest. I'm lucky in that, at least I am well developed in comparison to other girls I've seen with this syndrome. Then again, not that much. But, I don't know. It's a personal thing... In reality, when I have spoken to other girls, it's only really been me that would like to take this step. It seems like it doesn't appeal to others, they are fine the way they are...

Within the complexity of this, we have to understand that each new obstacle, whether biological or functional, adds to the effect of the devaluation of femininity. If a women presents XY chromosomes, and male gonads, she will never have a period, she will undergo clitoral reduction because it was considered too large, her body will have male features (the presence of body hair, a beard, body form, etc.) or may be infertile and not be able to achieve pregnancy, even with the help of technology: She will be much more vulnerable and the "sexual norms" will apprehend her with more virulence than those that, for example, have ovaries instead of testes, or present XX chromosomes instead of XY or, with the help of technology, will be able to start their periods and become mothers. The comparison chart below allows us to evaluate the level of vulnerability and abuse to which these women could potentially be exposed according to their condition:

	CAIS	PAIS	CAH
Menstruation	No	No	Yes A (Androgen excess treatment)
Fertility	No	No	Yes A (glucocorticoids)
Pregnancy	No	No	Yes A
Atypical genitals	No	Yes	Yes/No (different degrees)
Abnormal pubertal development	No	Yes	Yes/no (with treatment)
Vagina	Complete/partial absence of a normal vagina	Complete/partial absence of a normal vagina	Yes/No
Uterus and reproductive structures	No	No	Yes
Karyotype/Gonads	XY/Testes	XY/Testes	XX/Ovaries
Related health problems	Iatrogenic effects (osteoporosis, surgery) Low risk of gonadal malignancy	Gonadal malignancy Iatrogenesis (osteoporosis, surgery)	Dehydration Cardiac arrhythmias, etc. (during salt loss episodes). Adrenal crisis (hyponatremia, shock). Steroid induced iatrogenic effects (bones)
Proposed procedures	Gonadectomy. Vaginoplasty.	Gonadectomy. Vulvovaginoplasty. Clitorectomy. Gender policing	Vulvovaginoplasty. Clitorectomy. Gender policing

MRKH	SWYER	TURNER
No	Yes A (oestrogen + progest. combination)	Yes A (spontaneous in few cases oestrogen + progest.)
Yes A (egg donation. surrogacy)	Yes A (embryo transfer)	Yes A (embryo transfer)
No	Yes A (caesarean)	Yes A (hormone therapy, IVF)
No	No/occasional clitoral hypertrophy	No
No	No/Yes (with oestrogen treatment)	Yes
Complete or partial absence	Yes	Yes
Complete or partial absence	Yes (rudimentary uterus. Oestrogen)	Yes
XX/Ovaries	XY/Gonadal Dysgenesis (Hypogonadism)	XO/Gonadal Dysgenesis (Hypogonadism)
Iatrogenesis (surgery)	Gonadoblastoma. Iatrogenesis (surgery and hormones)	Kidney and heart problems, high blood pressure, diabetes mellitus, cataracts, thyroid problems and arthritis. Iatrogenic effects
Vaginoplasty	Gonadectomies	Plastic surgery (protruding ears, limb lengthening, breast implants, etc.) Gender policing

Negative medical experiences

In terms of negative experiences, they describe the lack of knowledge and insensitivity of medical professionals that attend to these conditions, the trauma of medical check-ups and physical exhibitions in front of doctors and medical students, the lack of interest and respect for individual experiences of sexual identity, sexuality, or desire, or recalling the pain caused during procedures or operations. In women with CAH, AIS or MRKH, we repeatedly hear complaints about the "shocking terminology" used by medical professionals —"categories are necessary, but doctors should be aware of the effect they have because language is not sterile and it should not recriminate" (P-Grap)—, about repetitive and unnecessary genital exposure in front of large groups and unknown doctors and students —"You see the student there taking notes... Well, remove him from here or ask me if I consent to this"(M-Grap2)—, or negative experiences related to vaginoplasty recommendations and procedures and the process to create a vagina through dilation:

> I went in and it did me a hell of a lot of damage. I requested an appointment with the gynaecologist. He asked me who the hell had told me to put that there. And I said, "Dr. [name of the surgeon]. And he said: “Well, I wouldn’t have advised it. You know what your vagina is like, to be putting things like that there. You’re ruining yourself”. And he was the one that advised me to buy the dilators. I had to do that. So, why didn’t he tell me to use dilators instead of telling me about tampons? Even the dilators didn’t solve anything (M-Grap2).

For specific syndromes:

Below, we give information about some of the problems or specific needs, divided into stages, and for some of the individual types of DSD, using the notes provided by Psych2.Hosp1 about the KS case as a basis and merely as a tentative way of drafting a future guide. Certainly, these needs may persist through different stages in life or may appear at different stages depending on each individual person, in addition to taking into account the diversity of each DSD— and the "degree of severity". We will see that some of these are reiterated by patients with different DSD and at different stages. This information should only be used as a guideline, or can simply be taken into account during the development of future projects.

Turner syndrome

Infancy/adolescence

- Learn about your own biological condition (the development of organs and what consequences it can have on your health).
- Understand the need to take medication on a long-term basis and acquire the skills to administer them (growth hormones are injected every day during growth and later, oestrogen, etc.).
- Living with differences. The "dualism of normality" and accepting difference itself (body form, height, development of secondary female characteristics).

Adolescence/Early adulthood

- Accept the absence of menstruation (a woman's rite of passage).
- Assume infertility without treatment, the need for HRT to become a mother (with egg donation) and/or consider other alternatives to standard motherhood ("you are a whole woman even if you are not a mother", or adoption).
- Accept your own sexual development as a woman (without the need to repeat the expectations of femininity, for example, the development of breasts).
- Isolation. The need to feel supported (by a peer group or reference group of women with Turner Syndrome).
- Receive dignified treatment from professionals, who cater to diversity and offer resources, facilities, and alternatives to treatment or treatment options.
- Accept the identity / the role of the patient (ongoing check-ups, procedures, medication, etc.).

Adulthood

- Overcome the fear of rejection, in addition to accepting and loving your differences. Self-esteem and empowerment.
- Assume infertility without treatment ("you are a whole woman even if you are not a mother") and the need for HRT to become a mother (with egg donation), as well as long-term fertility treatment.
- Overcome potential sexual problems (vaginal dryness, inability to orgasm, sexual desire, etc.).

- Receive dignified treatment from professionals, who cater to diversity and offer resources, facilities, and alternatives to treatment or treatment options.

Woman with CAH

Infancy/adolescence

- Learn about your own specific biological condition and the function of your body (also be aware of when you need to request help in response to a possible adrenal crisis).
- Understand the need to take medication on a long-term basis (corticosteroids, hydrocortisone, dexamethasone, etc.).
- Become familiar with the symptoms of an adrenal crisis or metabolic decompensation so that it can be monitored, and learn to self-regulate medication in accordance with stress situations (fever, illness, etc.).
- Living with differences. The “dualism of normality” and accepting difference itself (ambiguous genitalia).

Adolescence/Early adulthood

- Assume infertility without treatment, and/or consider other alternatives to regular motherhood (“you are a whole woman even if you are not a mother”, or adoption).
- Become familiar with and accept the possibility of masculinisation in response to the discontinuation of treatment.
- Accept your own sexual development (without the need to repeat the expectations of femininity).
- Isolation. The need to feel supported (by a peer group or reference group of women with CAH, AIS, MRKH or other syndromes).
- Receive dignified treatment from professionals, who cater to diversity and offer resources, facilities, and alternatives to treatment or treatment options.
- Accept the identity / the role of the patient (ongoing check-ups, procedures, medication, etc.).

Adulthood

- Overcome the fear of rejection, in addition to accepting and loving your differences. Self-esteem and empowerment.
- Assume infertility without treatment, and/or consider other alternatives to regular motherhood (“you are a whole woman even if you are not a mother”, or adoption).
- Overcome potential sexual problems (vaginal dryness, inability to orgasm, sexual desire, etc.).
- Receive dignified treatment from professionals, who cater to diversity and offer resources, facilities, and alternatives to treatment or treatment options.

Woman with AIS

Infancy/adolescence

- Learn about your own specific biological condition and the function of your body (XY chromosomes, androgen insensitivity, hormone production, absence of female reproductive system, etc.).

- Face the likelihood of gonadal surgery (gonadectomies, orchiectomy or orchidopexy) or the “normalisation” of genitalia (vagina, and external genitalia in PAIS,

- Living with differences. The "dualism of normality" and accepting difference itself (XY women, male gonads, absent or partial vagina, absence of menstruation, uterus and non-viable biological maternity).

Adolescence/Early adulthood

- Accept the absence of menstruation (a woman’s rite of passage).

- Assume infertility.

- Face the likelihood of gonadal surgery (orchiectomy) or the “normalisation” of genitalia (vagina).

- Potential masculinisation in response to the discontinuation of treatment (in the event that you have not had a gonadectomy in PAIS).

- Accept your own sexual development (without the need to repeat the expectations of femininity).

- Isolation. The need to feel supported (by a peer group or reference group of women with AIS, XY women, etc.).

- Accept the identity / the role of the patient (periodic check-ups for the risk of osteoporosis, surgery, long-term medication, monitoring of hormone levels to avoid secondary effects, etc.).

- Receive dignified treatment from professionals, who cater to diversity and offer resources, facilities, and alternatives to treatment or treatment options.

Adulthood

- Overcome the fear of rejection, in addition to accepting and loving your differences. Self-esteem and empowerment.

- Assume that it will not be possible to conceive a child and/or consider other alternatives to regular motherhood (“you are a whole woman even if you are not a mother”, or adoption).

- Overcome possible sexual problems (fear of rejection, engaging with new partners, etc.).

- Accept the identity / the role of the patient (periodic check-ups for the risk of osteoporosis, procedures, long-term medication, monitoring of hormone levels to avoid secondary effects, etc.).

- Receive dignified treatment from professionals, who cater to diversity and offer resources, facilities, and alternatives to treatment or treatment options.

In MRKH syndrome

Infancy/adolescence

- Learn about your own specific biological condition and the function of your body (the absence of menstruation and female reproductive structures —uterus, vagina—, etc.).
- Face the likelihood of surgery for the “normalisation” of genitalia (vagina).
- Living with differences. The "dualism of normality" and accepting difference itself (absent or short vagina, absence of menstruation, uterus and non-viable biological maternity or surrogacy).

Adolescence/Early adulthood

- Accept the absence of menstruation (a woman’s rite of passage).
- Consider the limitations of wanting to become a mother (a fundamental aspect of the social construction of femininity).
- Face the likelihood of surgery for the “normalisation” of genitalia (vagina).
- Accept your own sexual development (without the need to repeat the expectations of femininity).
- Isolation. The need to feel supported (by a peer group or reference group of women with MRKH, AIS or vaginal agenesis).
- Receive dignified treatment from professionals, who cater to diversity and offer resources, facilities, and alternatives to treatment or treatment options.

Adulthood

- Overcome the fear of rejection, in addition to accepting and loving your differences. Self-esteem and empowerment.
- Assume that it will not be possible to conceive a child and consider other alternatives to regular motherhood (“you are a whole woman even if you are not a mother”, or adoption).
- Overcome possible sexual problems (fear of rejection, engaging with new partners, etc.).
- Receive dignified treatment from professionals, who cater to diversity and offer resources, facilities, and alternatives to treatment or treatment options.

In Klinefelter syndrome

In relation to Klinefelter syndrome, Psych2.Hosp1 added the following information:

School plan

Infant school: adapting to peer group, motor difficulties, learning difficulties that will require going to the school psycho-pedagogic Evaluation Team (PET) for alternative treatment plans (early stimulation practices, psychomotor re-education).

Primary and secondary: adapting to peer group, motor difficulties, reading/writing difficulties that will require going to the school PET for alternative treatment plans (psychomotor re-education, reading and writing skills re-education, psychotherapy).

Adolescence: study skills.

Emotional adaptation plan

Commencing hormone treatment: how to tell a pre-adolescent about their illness and adapting to treatment.

Adolescence

Physical differences that the child will have in contrast to his/her peers.

Specific aspects of puberty

Sexual relations, difficulties

Valuing confidentiality: whether or not to make it public

Adolescence/Early adulthood

Assume infertility

The dualism of a different identity

Work through the “phantom of homosexual”

Adulthood

Assume infertility The dualism of a different identity

Work through the “phantom of homosexual”

Whether marriage is feasible of not. Self-marginalisation

Input from parents

The concerns and issues that affect parents which were brought up during the interviews are related to:

- Overcoming confusion, sorrow, and feelings of loss which arise when a child is born who is not "perfect". Living with imperfection is even more challenging when one of the first things they advise you to do during pregnancy, when they know that DSD is present, is to have an abortion (Ma-Nr5).
- Understanding the nature of intersex differences in girls and boys and whether medical care is required.
- Making informed decisions about tests and/or surgical procedures.
- Explaining the nature of intersex variations to relatives, friends or caregivers.
- Understanding the function of human sexuality and the diversity that exists.

This process requires them to overcome the following issues:

- Conflicts or obstacles that come up during interactions with medical professionals and the healthcare system.
- Information management —what to explain and who to explain it to— with regard to your sons, daughters, their partners or, in general, in any interpersonal relationships.
- Concerns about the future in terms of the stigma associated with being different, gender identity, gender roles, sexuality and intimate relationships.

Below is a section of the testimony given by Ma-Nr5:

> When the doctor taking care of me explained that it was almost certainly androgen insensitivity, he explained to me all of the worst case scenarios that could happen to my daughter and immediately asked me if I wanted an abortion. I had never even heard of the existence of something like this (I'm referring to intersex conditions) and together with the shock and unlikely prospect of a happy life after what the doctor explained to me, my first thought was yes, I want an abortion. I didn't want to bring a person into the world for them to have a really awful life. The time came to say goodbye to the baby and I remember speaking to it in my belly and I said: "I hope you will be born in a better position next time". I was resolute... // This idea stayed with me for a while, until the shock had passed (I think it was one day, or rather, the time it took me to start figuring out what AIS was). I contacted a geneticist and they began analysing me and my husband. In those days, when a week had passed, in which we had been investigated and the shock was starting to subside, we realised that our daughter wasn't sick, she would be born and we would love her.

The vulnerability of parents is undeniable. They have to make decisions without making mistakes. The ambivalent position that parents find themselves in is described as the feeling of having to protect their sons and daughters from a hostile social world, but at the same time, protect them and accept them as they are. They feel like they have to do everything they can for their children so that society doesn't reject them —including normalisation surgery— and at the same time, accept their individuality. During the interviews, the term "emotional trauma" came up which is used to talk about the dilemmas that parents suffer when making decisions; from the suffering stemming from their expectations, to difficulties in or lack of communication with their children.

One of the main requests from parents, resulting from the level of anxiety that it causes, is for an appropriate referral and the coordination of care procedures so that an accurate and timely diagnosis can be made. "One of the biggest struggles is for illnesses to be detected at an early age. If you see a girl with a short stature, a squint, abnormality of the palate, they should be able to pick up on that" (Ma-Turner).

Another one of the doubts expressed refers to the handling of information for the children. What should we be explaining to them about their specific DSD, when and how. This is an experience which induces a lot of anxiety. Ma-Turner sought help from an educational psychologist to address this predicament. She explained that "there are people that dump all of the information on you in one go. Just what to tell the school and that's it". But the educational psychologist she approached recommended that information should be provided gradually and frequently so that it can be digested, and that's what we did: "There's no need to tell them more than they need to know at their age. I wouldn't say: "You don't have ovaries, you won't have children". It has to be age appropriate.

Across the board, parents of people with DSD in the groups that were consulted reiterated the same anxiety, anguish, guilt and uncertainty in the pursuit of the best medical attention and in relation to effectively managing the differences that their children have within their close social network. High expectations incite extensive gender policing, in line with dichotomous models and exclusions of masculinity/femininity. On more than one occasion, the statement "the true sufferers are the parents" was echoed. H-inter believes that it is necessary to start working in this direction: "Help the parents with the process of "I have to offer him/her a solution now, right now", because obviously, "my child cannot meet all of these expectations". Then, you start to question all of these expectations because maybe they don't need to be met". Psychological assistance and clear information for parents is another one of the main requests: "Don't they realise that we feel lost. You need psychological help because you don't think you're competent enough" (Ma-Turner).

The experience is even harder in those cases when parents are faced with the diagnosis when a child is born with ambiguous genitalia, and the condition calls for a gender to be assigned. These parents display fear in response to uncertainty over their child's future relationships and their ability to have intimate sexual relations. Stress and shock are words that come up repeatedly, in addition to grief, sorrow, rage, anger, and shame. They share common reactions on finding out the diagnosis, in relation to the decision-making process for gender assignment, the operations that will be performed and the administrative procedures. They talk about experiencing disorientation, deep confusion and frustration. The stress suffered by these parents is even greater when doubts arise about the diagnosis or regarding optimal care.

Input from professional health psychologists

Initially, some medical professionals openly reflect on the privileged position that they seemingly hold, however, this is the same privilege that places them in a vulnerable position, since they have to accurately meet the expectations of their patients, and those of the general public. They are required to be experts, good advisers, that never make mistakes and answer all personal questions outside of the scope of diagnosis.

With regard to the difficulties and obstacles that arise in exercising their duties and providing medical care, once again, issues concerning coordination are highlighted, in addition to the need for a unified approach. Nevertheless, in order to unify the approach, a minimum level of consensus first needs to be reached about what the adequate care model should look like. With regard to normalisation surgery, this issue is often an insurmountable obstacle among medical professionals:

> I think that it would be worth unifying our approach so that we all operate in a similar way, don't you think? For example, we differ in other areas, especially when it comes to pathological conditions that are present from birth, about whether they should be fixed before the child goes to nursery. Because, normally, they constantly need changing, and if they have already been operated on before going to nursery, then no explanation will need to be given. We once saw a case of CAH in a high-class and well educated family, they used to go out of town —and it wasn't even a small town— to buy hydrocortisone so that nobody would suspect anything. Do you see what I'm saying? That's even considering that hydrocortisone is used for many things (Cap.CirPed.Hosp4).

IN SEARCH OF ANSWERS

The end of secrecy and concealment

Secrecy in medical consultations, at home, between couples, and in society, is nothing more than a reflection of a much more serious social pathology. We are talking about sexism, homophobia and transphobia. The recognised expression "intersexophobia" is also used.[vi]

In recent years, media interest in intersex/DSD people has been growing; people with intersex variations or differences of sex development are in increasing demand with the media, with requests to appear on radio and television programmes or in press articles. However, because secrecy continues to be a key issue in the lives of these people and their families, there is a lot of debate about finding a balance between the need to retain privacy and raising awareness of the topic. The support groups are clear about visibility being a priority, but not at any cost. Associations such as GrApSIA that openly pursue the social normalisation of AIS sufferers and eradicate the stigma which has always surrounded them, have felt obliged to protect their members to prevent their testimonies from becoming sensationalist stories or offensive headlines. In turn, they have developed a good practice guide for the media which aims to guarantee an "earnest and truthful approach" in response to what is considered to be a "complex and sensitive" subject. It calls for professionals to act with prudence and patience, it advises that the association is run by volunteers who have their own jobs and their own lives, and that they only have a small amount of time to devote to providing the services that the association offers (answering e-mails, research, updating the group's website, establishing contact with doctors and specialists, manning the group's helpline, etc.). Lastly, it calls for professionals to include the association's contact information (email address and website) in articles and programmes.

From the interviewees' perspective, the solution is not to pressure people into appearing on television shows, but to take advantage of the powerful media tools to raise awareness of the issue and to broadcast information that affected individuals wish them to transmit. With regard to the fact that women are primarily the ones who remain hidden and shrouded in anonymity, we must make sure that people understand the gender logics that propel this reality and condemn the implicit discrimination.

Parents demand the development of guides and information, but seem doubtful about the vulnerable situation that their sons and daughters find themselves in: "I can't post a photo until she decides to get out of there" (Pa-Grapsia) Raising the visibility of this community is considered a fundamental strategy in the fight against the social stigma that tows these situations, but parents feel conflicted about how to do that without putting their children at risk;

> Regarding the question of visibility, obviously, by the time these people are adults, they can decide for themselves. I think that she's still so young and that she will have to decide for herself when she's older. I don't know if that is how it should be, equally as a mother, I could say: "Well, this is how it is and I have decided to make it visible". In other words, I don't know (Ma-Grapsia).

In healthcare:

We have seen that many of the problems highlighted by people with DSD and their relatives are related to issues surrounding health and the medical care they receive. The Catalan Association of Klinefelter Syndrome expressed it this way:

> With regard to healthcare, we would say that, since KS was defined, many studies have been published to assess the cognitive and neuropsychological profile of it. These patients present a mild intellectual impairment of differing degrees, including particular deficits in comprehension, memory, language processing, and executive functions which may or may not be evident during childhood. That is why, on behalf of the association, we are asking for knowledge from the staff of the PET and the CDIAP (Centres for Early Childhood Development Services), treatment carried out by specialists in early stimulation, physical therapists (patients with SK require specific therapy to strengthen their muscles) and speech therapists for children who present difficulties in language development, as it has been proven that childhood intervention helps to improve social inclusion. As for those with SK who have reached adulthood without receiving this type of medical attention or who were not diagnosed during childhood, we are requesting labour market inclusion and social care which is personalised and conducted in collaboration with other associated professionals, such as the psychologists who take care of them.

The requests point directly to the very structure and organisation of the healthcare system: their healthcare facilities, their skills, the difficulty in accessing professionals with experience in the field, the obstacles that hinder their diagnosis and appropriate treatment, restrictions on getting a second professional opinion or because they are referred to a hospital in another autonomous community. Some of these administrative obstacles are the result of the low incidence of these conditions, which has forced them to be included under the umbrella of “rare diseases” or “low-frequency” by FEDER (Spanish Federation of Rare Diseases). Precisely because of its low incidence rate or infrequency, it produces a state of distress in the patient in response to the uncertainty of the diagnosis and the difficulty in finding the right treatment. (Canals, 2002).

P-CAH condemned the fierce controversy within the CAH association, which has caused many adult women and mothers of girls with CAH to become worried. This controversy is about the use of dexamethasone in 10 pregnant women, who previously gave birth to a girl with CAH (they are carriers) and that, in response to the possibility of having another daughter with CAH, have been prescribed this steroid, as a prophylactic measure to prevent the masculinisation of their daughters. Perhaps it is this research in the field of DSD that has resonated the most, due to its severe health implications and because of its ethical significance. There is a strong connection between CAH, lesbianism, disinterest in motherhood, or a preference for boys’ toys and masculine behaviour. Therefore, dexamethasone has been used since the 1970s to prevent the suspected physical and/or psychological virilisation or masculinisation, a result of the suspected effect of testosterone on the foetal brain. The controversy surrounding the use and testing of this molecule in these pregnant women is due to the fact that, in addition to not preventing the true health risks —for example, dehydration (through salt loss)— and resulting in major health risks for the mother, it actually seeks to prevent lesbianism and the supposed masculine behaviour of these girls (Dreger *et al.,* 2012).[vii]

P-CAH explained in detail how dexamethasone crosses the placenta and the hypothalamus. It is administered from the sixth week of pregnancy to women who have previously given birth to a daughter with CAH. Administration of the drug is discontinued if the XY chromosome is present when the amniocentesis is performed to check the karyotype. If XX is present, the drug is administered until the end of the pregnancy. The mother states that, out of the ten mothers who were given the treatment, two babies were born with no problems and the other girls had deformities, no eyes, no ears or cerebral palsy. This is why they made allegations that the doctors didn't inform them about these serious consequences and that, although the doctors are aware of these outcomes, they still view this treatment as a success. P-CAH bluntly asserted that: "I would prefer a million times over to subject my daughter to genital surgery than to subject her to these treatments. // She can lead a normal life with hyperplasia, but not with cerebral palsy".

The ignorance about intersex people or DSD and generally, many other rare diseases (RD) extends to many medical professionals, especially those who constitute the first link in the medical care process, those that occupy the position where the search for help begins. This refers to family doctors that work in primary care that play a decisive role in referring patients to the appropriate specialists. The ignorance about these conditions, for their part, increases the patients' vulnerability. These professionals, like those who work in small hospitals, have no experience in these situations and/or do not have the technological resources available to them to make a diagnosis. In these cases, they usually phone hospitals of reference to inform them, search the Internet, or send their patients directly to other centres. Regarding diagnostic tests, lab results, imaging, etc., we usually send the samples to these centres of reference, which causes a delay in receiving care.

Some of these medical professionals recognise these shortcomings in care and propose potential solutions to us, such as for all cases to be handled centrally in specialised units and hospitals that have better resources available and multidisciplinary teams (MDT) in place. Broadly speaking, the majority of people with intersex variations/DSD assume that the patronising care or the instability in their medical care process has been a generational issue and they are optimistic about the future of care.

Across the board of medical professionals that work in public hospitals of reference where care is provided for DSD, their opinion is that the solution can be found in tertiary level care in hospitals of reference, which have a multidisciplinary level of care available. The point at issue is to facilitate the referral or channelling of patients to these centres. As for Cap.EndPed. Hosp1, the centres should also be interconnected in order to make referrals possible, since, for example, at Hospital Vall d'Hebron they focus more on treating issues related to the pathological anatomy and diagnostics, whereas at Hospital Clínic they are experts in gender.

Transmitting information

The first medical consultation or the moment of diagnosis is often defined as enlightening, as well as traumatic: “I knew that something was wrong with me and I found the answer”, but at the same time, it reflects the lack of gender awareness among medical professionals. Individuals who are “sufferers” require more sensitivity from doctors when they are providing explanations and in the diagrams that they use. They call for an end to photographs of bare genitals; of genitals on the operating table, with people with pre-operative quadrants and lines marked out in black. Cap.EndGin.Hosp2 who is a specialist in gynaecological endocrinology, explained that:

> It has a psychological impact on this type of patient. I dedicate a lot of time to explaining the difference between chromosomal gender, gonadal gender and phenotypic gender. In fact, those with Morris [another name for AIS], are possibly the most womanly of all women. Because, obviously, they have no ability to respond to androgens. But in Swyer, for example,..., which is also XY, they have a uterus and are able to have children through embryo donation. Clearly, calling these people men is barbaric. I have met patients who have come from other centres... and they have been psychologically damaged because they have been given information which is a little, how to put it, crude.

Some women in the GrApSIA group recall negative experiences at the moment of being given information. They explained that, in group meetings, they were frequently shown drawings or images of gonads which are visibly testes or masculine genitalia, with a penis and scrotum. These are details which never go unnoticed among those present, and undoubtedly reinforce the perception of a “flawed body” with an undeniable masculine undercurrent. A consistent theme in the interviews is about the initial experiences of the first medical consultation in which a woman is informed about her AIS diagnosis, and she is immediately told that, if it wasn’t for an error in sexual differentiation, she would now be a man. “you should have been a guy”, “in essence, you are a man”. Or, in P-Roki’s experience, when he was diagnosed with MRKH syndrome, his identity as a woman was destroyed in the precise moment that his doctor said these words: “You’ve been lucky, I could have told you that we don’t know if you are a man or a woman”. This unfortunate comment has always made him wary of the biology of this supposed “man”, because of his flat chest, his preference for masculine activities and his refusal to wear dresses. Some women agreed that they could only make decisions about their own health when they felt free to ask questions.

Another widespread request with respect to information sharing is that it should be communicated in a positive way:

> M-Grap2: It’s the same thing that happens when you decide to explain it to someone and you have already digested the information sufficiently: you don’t convey the information in such a tragic way. We’ve talked about it, you’ve already gone through this process, so you don’t convey such tragedy. At the same time, perhaps some people understate it. People don’t give it much more thought if you don’t.
>
> M-Grap1: It makes me emotional to think that in twenty years time, a child will go to the doctor, perhaps when she doesn’t get her period,and he will tell her: “Ah, well it’s AIS, but it’s OK”. That

> she won't have to go to the doctor in secret to be treated for something, she deals with it and that's it. I think that by then we will have advanced a lot... That they won't need to explain anything, and if they do explain, it will be from a position of absolute acceptance (Discussion group).

Regulating sexuality in the healthcare sector

Despite substantial change in the relationship and dialogue between doctor and patient, one of the biggest medicals limitations is still centred around the regulation of sexuality. From a critical point of view, the medical model has based its interpretation of biology on a cultural model that is both sexist and homophobic; which is why people are considered "abnormal" if they differ from the binary model of "masculine/feminine" or "man/woman", perceived as the combination of XY chromosomes, testes, penis, etc. for men, and as the combination of XX chromosomes, ovaries, vagina, etc. for women. We have reiterated the widespread complaint that healthcare practices and the management of treatments are governed by assumptions. More specifically, that the gender categories used to refer to many people and evaluate their backgrounds (personal, sexual, "if you're married", "if you have a partner", etc.) or the recommendations governing healthcare practices or surgical procedures, do not capture the gender experiences of a significant number of individuals with intersex variations.

M-Grap2 explained that, according to doctors, vaginas regulate the *timing* of sexual relations, in other words, without a vagina, sexuality is not possible, and that wanting to have sexual relations marks the moment to create a vagina. She explained that there are no possible alternatives, "if you are a woman, it is not understood that you can have another form of sexuality without penetration. They don't explain anything else to you". M-Nr5 also claimed that doctors didn't question whether she was a man or a woman, since she had already suffered for not being a conventional woman In this respect, we make sure that the tests applied during psychological evaluations, such as the *Gender Identity Questionnaire* (GIQ) have a highly polarised and dichotomous view of gender.

The regulations also use a profoundly limited model of sexuality which does not offer possibilities to the diversity of real bodies:

> It is based of a series of expectations: how the genitals should look, how the relationship should be... / For instance, in *Sexing the Body*, Fausto-Sterling explicitly said that she was surprised by the fact that individuals with ambiguous genitals had managed to lead successful marital lives. Even she had been surprised. // You say: "Obviously, you share the opinion that, if your genitals are unusual, sexual relations cannot be satisfying". Yes, absolutely. You have to explain further then. I have done it. But it's true that when you have ambiguous genitals, before doing anything, you have to provide an explanation and you have to be very sure about what you want (H-inter).

In relation to men with hypospadias, H-Hipos explained that:

> There is a study about hypospadias that was published two months ago. What does a woman want sexually from a human penis? Sometimes our urethras are in a different place or we have what is known as curvature of the penis. In the end, the study

> showed that women don't really care where the urethra is". What I mean is that they operate on hypospadias at the site where the urethra is, but ultimately, it is not a sexual problem. If a guy has hypospadias, a girl wouldn't even notice if the guy knows what he's doing, if he has an erection, etc. "This is my body, this is how I am. And there's nothing abnormal about it". I think that abnormality actually comes from medical discourse, from "it cannot be like that". / " The problem is that penetration won't be possible". Not true, I have friends that have children. You can change positions. Foreplay and lubrication also help, the penis will go in eventually. There's trust between both people.

He insists that, for all of the training given to new junior doctors in molecular genetics and communication skills, it would be impossible to implement a new model of "patient-centred" care if these beliefs remain intact. A model of care which positively values the possibility of having another type of sexuality which is not based on intercourse and reproduction is actively called for:

> M-Grap3: What's with vaginoplasty? Or with dilators? In other words, why can't I have a short vagina and that's that? And enjoy my sexual encounters anyway. It's strange isn't it? You go to your appointment and they tell you that in order to have a sex life, either you will have to have vaginoplasty or carry out a dilation process.

> H-Hipos: We ask ourselves questions that ordinary people wouldn't ask. It's very important to have this question written down and, let's say, a standard but positive response for it. Then, I don't know. But for me, because I have a small penis, it's going to be hard for me to accept it. It's going to be hard for me to feel good like this, to feel proud like this. If I had found a more open person who had offered me a more positive outlook, it wouldn't have taken me years to accept myself. I would have felt more supported. That's what it's about, helping me psychologically with my body. I would have waited until I was 22 years old to begin my sexual adventure. I didn't know if I was capable of giving pleasure. But, it would have been great if someone said to me: "Yes, with a 10cm penis, it works perfectly, but it also depends how you move, how you perform, but there are other things that are important, such as personality". (Discussion group).

Competencies The MDT and expert patients

Barcelona has been and continues to be a city of reference within Spain for intersex and DSD medical care. This means that some health centres and some of their employees have a long history of catering for these situations; but, besides that, they have also become centres of reference and the recipients of many dissatisfied people from other autonomous communities who have arrived in search of an accurate diagnosis, help and specialised care . Among some of the greatest centres of reference mentioned in the interviews are:

- Hospital Clínic, with the most experience in adult endocrinology.
- Sant Joan de Déu Children's Hospital, specialised in paediatric care (the department of paediatrics of Hospital Clínic).
- Santa Creu i Sant Pau Hospital, with the most experience in gynaecological care for adults with DSD.

- Hospital Can Trias (Germans Trias i Pujol), with a long history of care for individuals with DSD, founded by surgeon Joan Martínez-Mora in the 1970s.

- Hospital Vall d'Hebron, renowned in genetics, diagnostics and research.

The last two were the most frequently mentioned by people from outside of Catalonia who requested to be treated in a hospital of reference in Spain. Other centres and private clinics were also mentioned during the interviews, all of which were discovered in response to dissatisfaction with public care. Some foundations with experience in treating DSD were also mentioned, such as the Puigvert Foundation or the Doctor Robert Foundation (The Autonomous University of Barcelona).

The most read and valued guide for medical professionals about DSD care in Spain continues to be the *Consensus Statement on Management of Intersex Disorders* (Lee *et al.*, 2006), a North-American and European medical care standard which is now known as "Optimal clinical management of individuals with DSD". The Consensus established that a multidisciplinary team is the recommended care setting and to which people with DSD should be referred for ethical care(Lee *et al.*, 2006; Hutson *et al.*, 2012). An expert multidisciplinary team composed of an array of sub-specialist paediatricians in endocrinology, urology/surgery, psychology/psychiatry, gynaecology, social work, nursing and specialists in bioethics.

During the interviews, we asked each of our interviewees about these teams, from the professionals who make up the teams in Barcelona's hospitals of reference, to individuals diagnosed with these conditions and parents, and also other medical professionals and social psychologists that work outside of the public health systems. The biomedical specialist responsible for and most familiar with these situations is usually the paediatric endocrinologist; however, as we have seen, and according to what medical professionals who were interviewed have said, the person who assumes the professional specialist role, *head of service*, coordinator and interlocutor with the patient and family, in these cases depends more on the tradition and expertise of each hospital, as well as the involvement and initiative of each professional. In fact, many people request that it is always the same medical professional that sees them, without any additional doctors or unknown medical students around, because of the requirement to bare their bodies all of the time, and the issue of intimacy and trust is fundamental.

With regard to the structure of the MDT in the hospital of reference where Cap. CirPed.Hosp2 works, he explained:

> Here, we [referring to paediatric surgery as the team in charge] engaged neonatologists, because it's a time, that moment of birth, when a diagnosis may be needed if a child is born with ambiguous genitals. We had and still have paediatric endocrinologists engaged, they are Doctor [name] and Doctor [name]. We have the laboratory engaged with Doctor [name]. On a molecular biology level, we have Doctor [name] or Doctor [name] from Bilbao is involved. With that in mind..., what we couldn't be and didn't want to be —because we couldn't and didn't want to be and we had never considered it— was to be alone. If they have done things in other places, we have taken advantage of this because it's not worth repeating these things, for cost reasons, etc. Later on, when they needed psychiatry, we

> engaged them too. And psychology, but fundamentally, psychiatry. Then, we collaborated with gynaecology and obstetrics for cases of GrApSIA in adults. We also received help from urology. In other words, we could say —without any word of a lie, quite the opposite— that we are multidisciplinary. We always pull in whomever we think can help the patient and nothing more.

We also asked which obstacles in particular impede the creation of these MDTs in our country, what would their opinion be about the optimal structure for these teams, and most importantly, whether they believe that this method will solve the real issues that affect individuals with intersex variations/ DSD and their families.

A significant portion of the people interviewed believe that, if these teams functioned in the way that the Consensus recommends, they would attain this level of optimal care. In order for that to happen, we must improve coordination, to organise for patients to be referred appropriately, as well as ensuring that there is adequate psychological care within the teams. They also claim that the problems that exist today occur because this model has still not been implemented, and because of shortcomings in the medical framework and the availability of staff and financial resources. Until now, both the treatment and referral procedures for patients in these cases have taken routes based on informal information and care, and have even been the result of random events in some cases. Cap.CirPed.Hosp4 relates in detail that, from meeting other professionals when attending conferences, for example, these other professionals get to know their level of experience, and when they are presented with a case like this, they make a phone call to exchange information, advice, doubts and/or recommendations, and the patients at most, only need to make a trip to the hospital to confirm the diagnosis and/or treatment, and then they go back to being treated by their doctor in their home town.

Cap.EndGin.Hosp2 explained the shortcomings of this type of patient care, and a possible solution through the creation of care coordination units:

> Many patients do not go to see anybody, they do not visit any professional because they believe that it will solve nothing, they remain silent. And others that do visit medical staff find that they don't know either... Because these are very uncommon pathological conditions. They do the best that they can, but they are unaware that there are places with specialist units where this type of problem can be treated. For example, Turner syndrome affects one in every 2,500 women. So, of course, in our area there should be 500 patients around, but we don't see them. Who is treating these women? It must be their general practitioners, and if they have a specific problem, they are referred to a particular specialist. I'm not trying to say that this is a bad thing, but what would be better is for them to be managed in a care coordination unit, because these patients usually have a variety of related pathological conditions. They have a higher risk of aortic dissection, a higher risk of hypothyroidism, etc. It is an extremely complex condition.

Similarly, both patients and professionals report difficulties in treatment when they move from the paediatric age group to the adult one. The problems could be solved, in part, by implementing a model of coordinated, integrated and continuous care:

> Well yes, I have also had major problems finding someone who will monitor my condition, most of all later on, when I'm an adult. Obviously, they help you more in the Paediatric department, but after that, you don't know where to go. Actually, they diagnosed me in a rather miraculous way. The paediatrician noticed that I wasn't growing as much as I should and diagnosed me at around twelve years old. And they were giving me growth hormones. Nowadays, it is usually diagnosed much earlier: there are mothers that already know that their two-year-old daughters have it. Hence, they give them hormones from a very young age (M-Turner1).

> Patients are monitored closely during the paediatric stage, but when this period finishes, these individuals end up in the general health service. They are enlisted as normal patients, but they have related pathological conditions. There are centres where they can be treated in a more integrated way, but they are not aware of these options, neither the patients nor the general practitioners know this. Although they can treat them perfectly well most of the time—I'm not saying that they don't have the ability to do so—, this is a type of patient that has the opportunity to receive more personalised care for their own specific condition. Something which is very common in Turner syndrome (Cap. EndGin.Hosp2).

Many professionals recall the scarcity of resources, and paradoxically, the under-utilisation of existing resources, because they are not very well distributed. For example, the Unit of Rare Diseases at Hospital Vall d'Hebron has a clinical psychologist available who attends to boys with KS and provides individual and group therapy to their parents. Despite stating the limitations in care (this is the only unit, the only psychologist, for all of the rare diseases), it also makes reference to the under use of services, due of a lack of knowledge among patients and their parents. In any case, both the patients and their parents complain about the lack of economic support available for treating health needs that are not covered by social security. In many of these situations, the routes taken in the pursuit of health intertwine in a labyrinth of medical centres, private practices, associations, etc. medicines or trips that involve an ongoing financial outlay. Ma-Turner detailed the care pathway and financial cost required to take her daughter to an educational psychologist to improve her ability to process information; to a speech therapist, because of the difficulties she has in pronouncing words due to her ogival palate; and to vision therapy, because she was born with a strong squint, etc. To all of this, she has to add the cost of all the medication which is not covered in full, and the fact that there are often long periods of time before starting treatment for the claim to go through the medical committee.

> It took a year to begin the growth hormone treatment because it had to go through the medical committee and be approved. [Her specialist] said to me: "They will give it to her because it meets her needs, but with the delays in Health..." I lost a year and a half because of the system. I thought about paying for it myself, but it would have been between 3,000 and 4,000 euros per month. One injection per day in the buttock, where it hurts the least, and they give you the treatment at the hospital pharmacy for several months. // Three year old girls are already being

> injected. We had to wait more than eight years and it could have been longer.// The speech therapist is not covered by social security because it is considered an aesthetic treatment. But her bite is all wrong, it is a result of Turner. // Vision therapy costs 60 euros each week. She was born with a squint because of weak muscles. It can only be corrected through surgery. We went through the health insurance and had it operated on. Social security was cut back. // Oestrogen treatment will start when she is ten years old, like with the other girls. Later on, she will be given others, one of them is the pill, so that she doesn't develop osteoporosis, etc. They have to do a blood test every six months to measure oestrogen levels, and to check whether the hormones are having any secondary effects, such as diabetes or thyroid problems. [Her daughter] started having hot flashes. [Her doctor] said to me that her body was calling for change but her gland wasn't allowing it. She already started developing breast buds. I have to pay for this medication. It's an oestrogen formulation that I pick up every two months and it costs 50 euros. And it does not end here.

Cap.Hosp1 emphases all of the collaborative projects that they have been developing in recent years and how they promote and provide support to international partnerships and meetings between professionals and “affected individuals” (DSD support groups). The most important one mentioned was the COST project (European Cooperation in Science and Technology) BM1303, DSD-net *A Systematic Elucidation on Differences of Sex Development* of the *Horizon 2020* project, and some initiatives for registries of patients with DSD on an international scale, such as the *I- DSD Registry*. This registry provides a means of exchanging clinical information between healthcare centres within a virtual environment, and not only among experts, with the aim of standardising guidelines and improving clinical practice and research in addition to the understanding of these conditions. In Spain there is the project for the National Rare Diseases Registry of the Carlos III Health Institute (ISCIII), coordinated and managed by the Institute of Rare Disease Research (IIER), and belonging to the ISCIII and the CIBERER (Centre for Biomedical Network Research on Rare Diseases). This registry has three different data entry points, namely: population-based registries with data provided by the autonomous communities; patient records recording patient outcomes through data provided by patients themselves, and the data provided by participating professionals, research networks and medical societies that maintain agreements with ISCIII.

In different ways, all of the proposals point to a "translational medicine", which is interdisciplinary and multicentric. In terms of a central place (or place of reference) which could be considered most appropriate for care coordination, some people claim that it should be the hospital and its MDT, "because they are usually the first to detect or receive individuals with intersex variations/DSD" or "because that is where parents release their anguish and grief", and for other interviewees, primary care centres would be the most convenient because they cover prevention and education. According to Gin.Sex1, the latter option would also help to destigmatise this population and to promote their health through a model which encourages independence and self-care. The gynaecologist recalled the care model of family planning centres in the seventies as "friendly centres, compared with the hospitals which were more aggressive". They were places that were easy to access where people were helped to overcome their fears or where women were empowered by their sexuality. The professional offered a whole host of ideas about how the system could be integrated, if it was organised by geographical areas or territories, with a team per area, and about how the team could be structured.

Psych2.Hosp1 proposes the creation of "road maps" that list the needs identified for each condition, as well as the material and human resources we have available: ranging, on the one hand, from attending to everything that is anatomical, with an educational-psychological healthcare team that addresses issues relating to attention deficits or writing problems (in relation to KS), to educating families who have an intersex/DSD child. In this respect, it is a widespread demand for these people to be taken care of without losing sight of their needs at specific ages or stages, the right timing. In cases of KS, information must be provided during the school-age years —to inform the family about the extensive help available to confront phantoms, such as homosexuality—: to educate them about sexual identity, infertility and starting hormone treatment or issues related to body image, for example, with a view to meeting sexual partners or being nude at the gym. In TS cases, M-Turner2 requested for these stages to be covered in medical care —check-ups for height, weight, bones, diet, vision problems, school performance, etc.— in accordance with the emotional and psychological needs of each age group —"from children and adolescents to adults, to explain, for example, the effects on libido, delayed sexual development, vaginal dryness, inability to orgasm, etc."— with information that breaks away from sexual taboos in society and about whether or not sexual therapy is needed.

To carry out this study we followed the routes taken by people diagnosed with intersex variations/DSD in their pursuit of biopsychosocial healthcare. We asked them about the pathways that had provided them with answers, solutions and relief. Health professionals that work in biomedicine featured in these pathways, but on many occasions these routes go beyond the guided biomedical care which is public and free of charge. This is about professionals that, according to some interviewees, have offered them a more devoted and personal level of care, more time and, above all, alternative options. We were able to get in touch with some of these professionals. There are some that agree on the need for MDTs, but composed of more professionals than recommended by the Consensus, or of different types of experts with diverse philosophies and ways of understanding healthcare. Gin1 spoke about the need to personalise care, especially in relation to gynaecology, which is the "only gender medicine", and claimed that, at the moment, "medicine is not serving the needs off women, rather, it is serving itself". The gynaecologist proposed the creation of a multidisciplinary space as a solution, which has room for professionals in psychology, sexology, physiotherapy (e.g. for the pelvic floor), experts in body awareness, genetics and gynaecology.

Rehabilitation and sexology are other recurring requests. In the case of women who require extirpation surgery or clitoral reduction (predominantly those with CAH and PAIS), dissatisfaction and doubts have been expressed about the pleasure that they are able to feel, or about not being able to feel pleasure at all, etc. H-inter recalled the case of a girl with CAH who had undergone clitoral extirpation and was requesting help. The expert ended up putting the girl in contact with a sexologist that worked with the pelvic floor, who said: "Look, there are ways to rehabilitate in these cases. That means, with exercise, hard work, it's possible to recover from the loss of feeling, you may not be able to reach a full orgasm, but it is possible to make sexual relations less painful, don't you think?".

The inability to centralise care within the conventional biomedical care systems is compounded by the complexity of coordinating external professionals. Some interviewees explained that every hospital and every professional has their own patients and they are very reluctant to give up direct responsibility for them.. In this sense, the creation of a work network was proposed as a possible solution. This network would be coordinated by these professionals and hospitals, "so that they don't have to lose patients". However, M-Grap1 pointed out the resistance from the hospital doctors to incorporate external professionals within the MDT, and at the same time, the need for them to be incorporated because "medicine doesn't have all of the answers to an issue which is so closely related to intimacy": "You find yourself dealing with a very intimate topic, but one that is only being treated from a medical perspective, which is not intimate at all". Using a particular anecdote about a moment of disagreement with another medical professional, Grap1 exemplified the paradox:

> When you want to make them see that, of course, it's normal for this doctor to get a little..., he's cautious about having a sexologist in the hospital, because he's never been taught that we have needs that go beyond medical needs. More precisely, we have needs that go beyond medical needs because it's about our intimacy. "I have only ever been treated in a medical context", and something intimate cannot only be treated in the medical sector. I have a series of deficiencies and, evidently, we need a sexologist speaker at this conference, and speakers from other disciplines as well, because we have deficiencies that they haven't resolved for us, that we haven't been able to resolve, because there hasn't been any correlation between what is stipulated medically, academically, what is written... and the suffering. This is the precise reason why it has been categorised as something which it goes far beyond. And from here comes the discrimination. Maybe I am wrong but, I understand that this doctor gets defensive, that's normal. So, what can we do? Raise awareness and visibility, get people involved, I find it extremely difficult but we have to do it. I know that we have to do it. And they have to jump through hoops and carry out training and swallow clinical guidelines, or whatever. But, somehow, it will happen. Because we can't always be holding conferences, we have to go beyond that.

Similarly, it is reported that there was resistance to creating the network of coordinated action outside the scope of the hospital and away from medical care. Some of the interviewees believe that medical professionals should be in this network group, but that it should not be them that coordinate the management of intersex in the field of psychosocial care: "I believe that it would be important for the medical community to participate, because, at the end of the day, medical personnel are the ones who are in contact with the family members. I won't be at the neonatal unit".

We must not forget the traditional discipline of medicine, which has trained doctors to have an extensive range of technical knowledge, but which has neglected the psychosocial aspects that enable care to be free from prejudice, such as communication skills, bioethics or expertise in cultural and sexual diversity. The majority of people asked did not venture to propose or devise a viable method for assistance or care. Even though it is generally perceived that the City Council and other social authorities occupy an unclear position from which they do not really know how to help, some people believe that this is the ideal position in terms of proximity, easily located and visible, and free from the labyrinth of the Generalitat (regional government of Catalonia). It is also portrayed as a position from which holistic care can be coordinated and secured, which focuses more on the emotional and psychosocial aspects. In this vein, the integration of these ethical and social elements into medical study plans has also been proposed.

Some of the interviewees tend to consider another care model, based on "intervention-assistance" or "medication", which is less centralised and separate from health centres. Some of the testimonies included the example of Trànsit (promoting healthcare for transgender people), a unit which has disconnected itself from the traditional gender identity development units (GIDU), which refuses psychiatric pathologisation, and which offers psychological help or support, advice about treatment, the provision and prescription of medication, contact with associations or groups and with surgeons in the event that surgery is requested. LGTBI1 affirmed that "the current model is risky and must shift towards this model of intervention-assistance or medication" which transforms the doctor or professional into a guide, an advisor or a partner, and patients into responsible subjects who make informed decisions. Ma-Grapsia expressed the same sentiments: "Doctors need to accept their role as partners, rather than mangers".

The shift towards a patient-centred model, that manages and involves them in their own self-care and health, is unstoppable. Some of the respondents reject the current concept of the MDT because expert patients are unable to form part of these care units. M-Grap3 explained how, in other countries, such as the United Kingdom, support groups are part of these MTDs. This rejection is justified using the explanation that it is an issue of medical confidentiality, but this secrecy only makes sense in a hospital environment, it shouldn't be an exclusive place from which biopsychosocial care is implemented. Another one of the proposals encouraged the creation of patient groups from a social institution that can participate in the MDT.

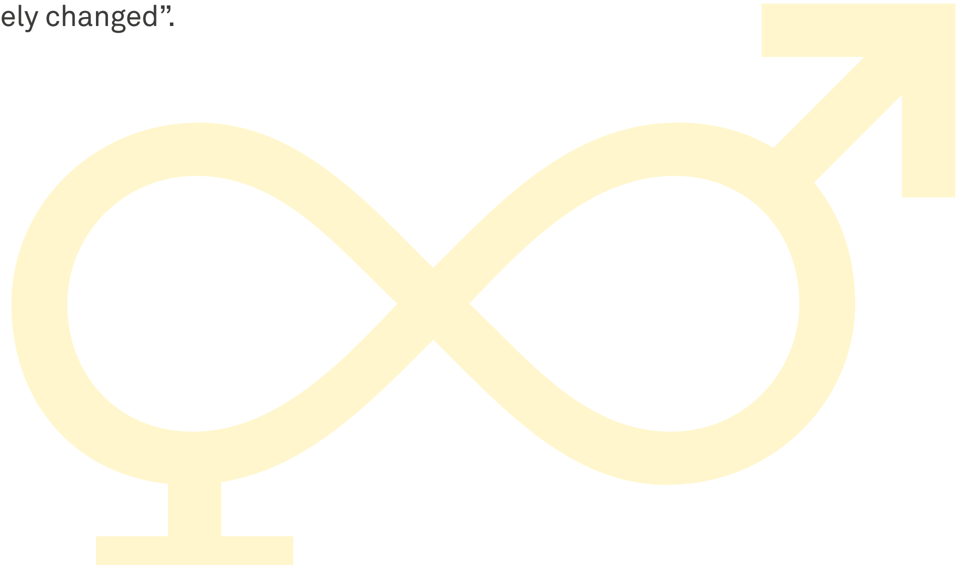
> Perhaps this group could be included in all hospitals where the endocrinologists..., well, it's about there being a protocol for endocrinologists to have more doors than just the surgeon's to knock at. They can't even call upon the psychologist: the route is endocrinologist-surgeon and gynaecologist, at most. Well, at least in our case. And perhaps if they form part of that, they can create multidisciplinary groups that we can be in too (M-Grap1).

Patients' participation in health is presented as a complex scenario in terms of the doctor-patient relationship;

> M-Grap3: This is the issue of the doctor-patient relationship: that doctors have risen above because people have needed to transfer this responsibility to them. It's complicated, sometimes.
>
> H-Hipos: Yes, because they taught us that this is the path.
>
> Ma-Grapsia: Yes, both of these situations exist. Doctors who don't want people, the patients, to be responsible for their own lives, and people who don't want this responsibility. For this reason, [doctors say] if this person doesn't understand what I tell them, why should they go and see another [doctor]? (Discussion group).

Cap.EndPed.Hosp1 explained that the current intervention focused care model is shifting to a more personalised model that respects the opinions, references and information of parents and individuals with DSD. "Nowadays, parents have a considerable amount of information and the care must be personalised, in accordance with the information they have. If parents prefer to preserve the physical integrity of their children, this decision must be respected and supported. Fifteen years from now, this will have completely changed".

They also proposed the creation of their own care units; as an intermediate stage, a connection between hospital, social and family life. Traditionally, the places designed for this purpose were the health centres. According to Gin.Sex1, the health services portfolio must guarantee the existence of this unit in certain healthcare departments or to attend to a particular portion of the population. This unit would be comprised of professionals in healthcare, psychological or psychotherapeutic care, sexology and social care (all of which employ gender perspective, and adequate and modern knowledge about the specifics of each condition). It is also conceived as an intersex/DSD training and research centre, which could become a specialised training centre for professionals in the city and a centre of reference for the rest of Catalonia, and even Spain. In this way, it would also serve as an assessment and monitoring centre for all of the professionals that provide medical care to this population.



Awareness and integration from a psychosocial perspective

Psychosocial care in the management of intersex/DSD is perceived by those diagnosed and their parents, as a mere label which is politically correct, but which does not exist in practice. Psychological care has frequently been listed as in short supply and is commonly requested by all social players. However, social care, which is more closely related with stigma, taboo, isolation, guilt, raising visibility and awareness, family issues, sexuality, sexual diversity, etc., remains forgotten and is even made to disappear behind other needs, which are usually medical. H-Hipos believes that it is a mistake that doctors are currently held up as experts in the psychosocial issues that adversely affect intersex people, “as if medical and surgical knowledge would cross over into any social issues”. In this respect, many surgical procedures which aim to help people are considered inadequate or unnecessary, “when the core problem, which is emotional or affective, remains unresolved”.

> H-Hipos: Years ago I met a woman who said that her ex-fiancé committed suicide partly because of that, because they had operated on him twice and he was a broken man. And one day, he threw himself under a train. The girl explained it like that. This is when I understood the importance of saying that surgical reconstruction has a very important element to it, which is that it is psychological too. Move the urethra to the tip, for what reason? / It’s more important for the person to be able to accept who they are. That they are complete without surgery.

> M-Grap3: Surgery is a tool. It can be positive or negative. If you want to have it, then do it. But it’s always up to you to decide, isn’t it? (Discussion group).

P-Grap also exposed issues that are not covered by medical wisdom. GrApSIA gave an account of the history of their association and of how each year, during the medical gatherings that they used to organise, initially they would simply listen passively to the doctors. However, little by little, they started to participate more, delving into psychological and social aspects, to defend the fact that AIS was, at that time, a “biopsychosocial syndrome. Therefore, we started addressing the secrecy, fears, solitude, isolation, the need to reduce and eliminate stigma, taboo, the acceptance of differences, sexuality, family conflict, etc.”.

Cap.CirPed.Hosp4 reflects on the issue of isolation and blame, and refers to failed attempts by professionals to promote meetings between patients and parents, as well as the need to create an organised care network: “They are people who, until now, have wanted to remain isolated. Because a kind of primal instinct sticks with them, guilt-related, doesn’t it? The simple question about whether it’s a boy or a girl… I remember a case in which the young girl should be a —girl— but the mother still couldn’t accept it. They were always asking for help, but, of course, moving about here… There was no organised network, which would be ideal, but we have tried to improve the situation on this level”. However, in the hospitals of reference that we have spoken with, initiatives to organise psychological support haven’t been successful and experts talk about the difficulties encountered by parents and patients in organising psychological support or therapy groups.

> They have tried, but any time that the families have met —one could be from Murcia and the other from Andalucia—, and on the occasions that they’ve been together, they hav-

> en't spoken to each other. They don't want them to know anything. Because that's like everything. By denying the evidence, you are creating a series of phantoms. Firstly, they come from many different places. Secondly, they cannot commute to this kind of degree. And thirdly, particularly in the paediatric age group, it's the parents you have to deal with. The parents don't want that. / After that, I would say (but I can't prove it) that when they have been corrected, surgically, especially the most common operation, which is hyperplasia, they can keep lots of things inside, can't they? They see that the child has genitals... Look, the best "compliment" I received was from a mother from outside of Spain, when they operated on the girl, who was already three or four years old. She said: "She has turned out just like her big sister". In other words, there was nothing else wrong, she had a hypertrophic clitoris and some other extra tissue. When they see that at school... There's another type of pathology which can pose more problems: when a girl, like the ones who come here, eight or ten years old, have an enlarged clitoris and have spent six months to a year getting changed without any of her classmates seeing it. That is a problem, isn't it? But they are isolated issues and they come from different places. We've thought about creating psychological groups for different levels, but it wasn't viable (Cap. CirPed.Hosp4).

The truth is that, until now, and according to the interviewees, psychological care and emotional support is always covered in part by support groups or patient associations (face-to-face or via WhatsApp chats), with independent or private psychologists. The only free psychological care mentioned is offered by the Unit of Rare Diseases at Hospital Vall d'Hebron (individual or group therapy for parents of KS patients) and the initiative organised between FEDER and the Department of Social Psychology at the University of Barcelona. Here, the students' training consists of overseeing groups of patients and parents with the same condition or different conditions with similar characteristics (face-to-face or via the Internet). Other MAGs created by the rare diseases CIBER (CIBERER) have been mentioned, which are available online and are overseen by psychologists.

AFAPAC is one of the associations that, despite its small size and the fact that it only deals with conditions related to growth in the form of intersex in Turner syndrome, insists on the need to work on the social integration of these people. Its lines of action are based on the actions of citizens, such as a touring exhibition which raises awareness about why someone with these conditions cannot become a lawyer, about the failure of schools or issues in the workplace. Furthermore, they produce materials for professionals which outline pathological conditions related to growth and design labour market inclusion plans.

The model proposed by Psych1 didn't pinpoint any particular system, but it assists with access: the first visit to a psychosocial care centre, which offers information, resources and community work (family, school, intercultural support, etc.), where group or physical therapy can be organised, all with a view to depathologising intersex conditions. This psychologist insisted on the need to oust "medical issues" from the centre, because, "by following the same steps as the LGTB movement, doctors become less interested the more that people empower themselves". The professional considered that medical care is and has been standardised, which makes it necessary to address this issue taking into account the diversity of experiences and expectations of life. Accordingly, she proposed drawing up best practice recommendations based on the theoretical framework that evaluates, for example, the results of research or studies about the risk of gonadal malignancy, the scales used to assess behaviour and quality of life, and that highlight their methodological biases and/or implicit heterosexism.

Neither the hospitals nor the MDTs seem to be able to fulfil all of the needs of the patients and relatives. In fact, many of the routes taken by people with DSD are pursued outside of the public health sector, and even outside of allopathic and biomedicine. A significant portion of the therapies and care pathways pursued are occupied by alternative therapies. Currently, new professionals and spaces are in demand: group therapies, Gestalt psychology, mindfulness, family grouping, yoga, pelvic floor therapy and Tantra, are some of the therapies sought and mentioned in the interviews because they have proven useful and provided solutions. As M-Grap2 said, “belly dancing has helped me to come to terms with my body”. Various techniques are highlighted; for self-awareness, self-acceptance, improving self-esteem, problem solving methods, such as the *Ho’oponopono*; as well as other therapies that enable them to explore and get closer to emotional pain, such as the Metamorphic Technique, etc.

As for Ma-ascatsk, given that the parents’ main problem is accepting what has happened to their children, she considers that medical information is inadequate:

> Parents end up with extensive medical information, but nothing on an emotional scale about how to cope, they don’t even know what they have to accept. In cases of Klinefelter syndrome, many of the initial messages are based on data from psychological studies, on IQ (intelligence quotients), where the only information they receive says that their child is borderline and they believe it: “You think what you think, in that moment they stop seeing the potential that the child has. I’m going to think that my child is borderline”.

The truth is that in the few studies that exist for this population in Spain, such as *Sameklin* about mental health in men with KS[viii], their results associate a chromosome with a series of personality features and behaviour, which are not explained in relation to the context, to the discrimination that they may have suffered or the bullying at school. As for KS, Med.Farm1 takes the view that the only solutions given —also psychosocially— are all resolved using one molecule, testosterone. “All of the psychosocial needs are resolved through an injection of testosterone. Currently, the three-monthly Reandrón treatment is not available on the market. This injection causes patients to feel super-powerful at the time, but later the downer is very obvious”. This same professional called for less drugs and a type of care that “prescribes social solutions”.

Gin1 insisted not only on the need to rethink and consider that we are not offering the proper psychosocial care, but also that we should offer a level of care that transcends different generations. The MDT does not provide this psychological and psychosocial care in the majority of centres. Neither is biopsychosocial health provided for in the health model of the care sector, whether in hospitals, support or treatment networks. These are purely biomedical, with medical professionals that work on an ad hoc basis and only sporadically with clinical psychologists.

There is a noticeable need to raise awareness and provide education about the psychosocial and sociocultural dimension. As explained by LGTBI1, since a large proportion of problems are related to a cultural model that rejects difference and is heterosexist, a significant number of the procedures should be addressed in that direction. In this respect, he affirmed that many of the personal problems that they face correspond to those of other transsexual people.

In Psych2.Hosp1's opinion, once any possible or potential health problems are under control, in the event that there are any, the main requests concern issues related to identity, to "losing one's identity", to the stress and emotional trauma of past events, and to parents. He considers that an essential task resides within the domestic context, in the management of guilt —especially in genetic conditions— and the pressure that is observed in this area. As the psychologist explained, in other cases, like KS, poor performance at school can emerge, so there is a need to promote supplementary classes and mentoring at school, and also psychomotor problems requiring rehabilitation, etc.

As for Gin.Sex.1, the key is to shortening the period of suffering, shame, anguish and loneliness for everyone involved. "That should be pursued in healthcare". Indeed, we observed how these stories normally start by describing the lack or complete absence of information and secrecy in the family. Above all, we repeatedly hear about the information provided in the first medical consultations being full of gender stereotypes, and sexist and pathologising language which appears to have an impact on patients, their self-image and self-esteem. Over time, after prolonged treatment journeys, many people go to experts in psychology or sexology or other therapists or treatment types that are not included under the umbrella of free healthcare procedures. This search for solutions and empowerment usually takes decades, if not an entire lifetime. Shortening this suffering would mean expanding the care model.

We can see how a team of experts is forming, in addition to a healthcare model which is concerned not only with health issues, but also with psychosocial and sociocultural issues; one that is moving out of the hospital context because it is including the people with intersex variations/DSD themselves and their families among their experts. In addition to all of the specialisms already mentioned, in this model there is also room for nursing (more personalised training for health-disease-care), social work, social sciences and humanities, and experts in gender. Lawyers are also considered as essential figures (especially in streamlining the referrals procedures, changing doctors, easy access to medication, claims, etc.)

Training and education among professionals

Within the list of proposals, training for health professionals appeared as a priority. Proper training should cover all the principles of respect for intimacy and diversity (physical/sexual), the accomplishment of true informed consent (in which all options are provided) and guidelines that explain how and where to refer patients when you are not experienced in the subject, and to recommend support groups after a diagnosis has been made. Clearly, before the needs that we have already mentioned, training and updates are required in medical knowledge of DSD, using the most recent research conducted by leading groups on a European and international scale. In organisations like GrApSIA, daily contact with medical teams, the empowerment of the organisation, together with the confidence built up over the years, has resulted in more authentic and straightforward dialogue between all parties. These women feel like they have managed to educate and raise awareness among medical professionals with whom they collaborate regularly, about issues which they consider to be crucial.

> Ma-Grapsia: This is the education we should be giving to doctors. By starting every conference with a testimony.
>
> M-Grapsia3: I think that's important. That is what generates change. Without that, these doctors go to medical conferences, with a PowerPoint about blood and guts, but it doesn't serve any purpose (I don't see anything good about a surgeon's PowerPoint). We haven't achieved much, almost nothing. We've managed to gradually educate our own general practitioners. But the rest don't understand; those that have always been there, I think that, despite having a certain level of awareness —which is why they have been with us—, they have changed over the years and understood the reason for this. For example, not long ago, when I was speaking with [name of doctor] they said to me: "Yes sir, yes, it's a girl the same age as you", and I thought: "And you didn't even tell me anything, it didn't even occur to you". "Yes, from the same time, the same age". It didn't even occur to him, and I think that now, after X number of years, it would.
>
> H-Hipos: I did ask if they knew of any other men with the same condition as me and they told me that, because of medical confidentiality, the couldn't reveal any information. Because of medical confidentiality.
>
> M-Grap1: Of course, you don't need to give me their contact details, but I'll give you mine for you to give to them. In the end... I think that the same culture is ingrained in them, they are like car mechanics; they fix things. For intimate and emotional things, they don't know what you're talking about. Some of them do, they are different. Just like fixing cars, they fix bodies. You go there and say, just like having a broken wheel, that you have a broken child. "This is how we fix the wheel. Relax, the urethra is the same. We will replace the urethra and that's it" (Discussion group).

Normally, it's the more active and involved adults in the support groups that believe that an important part of training should be carried out by expert patients:

> Medical training is basic, isn't it? I'm not referring to the fact that they have to take a course every year... Or do they. I don't know. But, at the very least, awareness. That can be achieved if they take us in account. In other words, when we talk about multidisciplinary groups, we are say-

> ing that there's a series of medical disciplines that can work together to help the patient. But the patient, perhaps, should also be part of that network. And that's the end of it: training for doctors should happen here, so that they also listen to our voices. In the end, you only learn through experience. A little, I think. And up until now, they have only learnt from books (M-Grap3).

A potential strategy suggested to implement this training, is "therapeutic role playing" workshops, where professionals can put themselves in the shoes of the parents and the patients.

The majority of individuals with DSD interviewed pointed out that the medical information they received during their care pathway was scarce and awash with gender stereotypes and heavily burdened by stigma. Sensitive care, free from heteronormative prejudice is called for in the reproductive and sexual sphere. Also evident, is a rising need for awareness concerning the sociocultural dimension of intersex variations, to reduce the stigma placed on this group. It is not possible to improve health and social care for this community unless we understand the sexist, homophobic, transphobic and heterocentric sociocultural mechanisms that control life, and until the professionals who take care of the biopsychosocial health of this population, who educate and inform the general public about these issues, are aware of the gender stereotypes and bias that pervade medical recommendations and procedures. With this in mind, one of the pleas made to the public Administration was to guarantee adequate training in sex/gender diversity, as much for professionals in healthcare, as for those in education, social services justice, sport, communication, etc. and for professionals to be obliged to report discrimination or violence for motives related with sex/gender diversity. Gin.Sex1 considers that training courses in sexual diversity awareness need to be organised as a matter of urgency for medical professionals, and proper attention needs to be paid to sexual diversity in primary healthcare. Along the same lines, M-Grap3 recommended using audiovisual material in this training. Namely, she spoke about *Yes, we fuck*, a documentary which sheds light on other non-normative sexualities that do not conform to the expected standards, from people with functional diversity.

It has also been stressed that the training must be ongoing, so that professionals can stay abreast and up-to-date which the latest research, networks and/or protocols:

> Start developing and creating materials that are extensive, informative and comprehensive enough for professionals to have at hand when these situations arises; train other professionals and ensure that this [promotion] nurtures our abilities and improves the tools we have to carry out a good job with LGTBI clients and patients, if we don't do this, there isn't anything available, and you realise this when you start working in the field. You think: "What they taught me at university was good", but what we say now about doctors is that, your training only takes you so far, and when a situation like this arises, you think: "what am I going to do? If I am honest as a professional, and I recognise that I don't have all the tools, what am I going to do?" (H-inter).

Bureaucracy and administrative procedures

Cap.Hosp1 emphasised the problems that parents come up against during administrative procedures regarding Civil registration, legal terminology and systems, when a gender change is required (because it's considered that there was an assignment "error" at birth). Along the same lines, Ma-Nr5 explained the difficulties that her and her partner encountered when they had to change the gender of their daughter at the Civil Registry office when she was still a baby. In addition to coping with the social pressure of explaining to the family and everyone around that he was now a girl, having to wait a year for a judgement, visiting a forensic doctor, and seeing how slowly the process was unfolding, they decided to hire a lawyer to speed up the simple change requested, rather than a change of gender, an assignment error. Among all of the changes in documentation, the one that took the longest was the change of gender on the social security medical card, something that resulted in a lot of confusion at medical centres, where the name of a boy would be called out, and the parents had to keep giving explanations. The mother explained that, although they were able to pay the 900 euros in lawyer fees, many families are not in this position. This is the reason why she demands that bureaucracy is simplified and speeded up, in addition to it being a cost-free process. To this, she also added that the Administration shows very little respect when managing gender reassignment in their documents: "It's the *vox populi*. In the family book, the part about birth is crossed out. That could be a problem in the future, if you need to show your book to the Police or to participate in competitive sport". The mother recounts the need to create a protocol to respond to the birth of people with atypical genitals: "Most importantly, in addition to training, it's having the protocol to respond to this type of birth. For me, it should be obligatory, in response to a case of genital ambiguity, to carry out the relevant tests before deciding on the gender. That would have saved me from a lot of suffering and stress. It would have been useful if they had given me actual information, not from the Internet. In other words, the procedure should include giving information about intersex conditions to parents, explanatory guides, like those produced by *DSDfamilies* in the United Kingdom, with the names of some associations. With a view to getting rid of any administrative procedures, a proposal has also been put forward to promote legislative initiatives that recognise the right to having no gender recorded in the civil register..

Participation in associations

Patient associations satisfy the basic needs of people with DSD and their families: combating isolation and the fear of stigma, promoting recognition and improving self-esteem, offering information and expert knowledge through experience. Until not so long ago, they were discouraged by numerous medical professionals, however they are now hailed as an indispensable source of help and support. In fact, although some medical professionals try to encourage their patients with DSD to go to meetings held by the most active groups, like GrApSIA, they believe that the initiative must by taken by the patient, and that professionals and institutions should only help, support and attempt to foster these activities.

The associations that we spoke with were created through the initiative of adults with DSD, or mothers and fathers. In the most active associations, such as GrApSIA, both adults and parents talk about what it was like before and after discovering the association:

> All the while, I kept on searching the Internet until I found GrApSIA, that was the start of me having a before and an after. At the time of gender reassignment, with a million questions, the reality of meeting the parents of girls with AIS and, above all, adults who were leading completely normal lives made such a big difference, I don't know how to put it into words. The information that they gave me helped me to know what questions to ask the doctors. Mostly, they gave me strength to be able to go through with the gender reassignment. It seemed like an impossible task to explain to all of the parents at my other daughter's school that our child who was, until then a boy, would become a girl. // Why did GrApSIA signify a before and after for me? In the meeting, I met women with AIS who explained the situation to me, women of all ages and parents with daughters of all ages too. They all shared their experiences with me and understood me. I saw women laughing, happy, living a life like any other person. And seeing them was like seeing my daughter as an adult, seeing that she could have a normal and happy life, just like any other person, where her differences would not matter. That brought me peace and a sense of hope that I hadn't felt until then. As I got to know them better, I was able to ask them thousands of questions that the doctors hadn't been able to answer and I requested a lot of advice from parents about how to handle the various situations that were arising. That made a great difference to how I viewed my daughter's condition. Speaking to one of the women with AIS, I asked her what she would have wanted her parents to do and what they didn't do and she said: "Don't give it so much importance". That really stuck in my mind and I hope to be able to do that. It doesn't seem so terrible any more, not like it seemed before meeting the girls from GrApSIA. Now it just seems like a different condition and that's it. She's two now, and she drives us crazy, with love and worry! I have a view of intersex conditions that is completely different from the terrible thing that it seemed at the beginning. What we don't know scares us. But, she will have a lot of things in her favour when she grows up, to be able to accept herself and her condition. She will have GrApSIA, where she will be able to meet women like her and girls of her age to share experiences and doubts. And she will have the acceptance of her parents and sister, who will support her in any decision she decides to make about her body (Ma-Nr5).

Often, the systematic pursuit of support associations is related to the lack of positive information, as well as our significant needs, which are not covered by the healthcare system.

> I found the association because I was totally lost and I didn't know anything. // I'm lucky, but there are girls for whom the syndrome is more noticeable than mine. I don't know if that will change as I get older. Then, you feel quite uncertain because, obviously, nobody can help you..., at least, not here in Catalonia. Of course, I would like to know more about the syndrome, about what I have (M-Turner1).

The vast majority of these associations hold annual meetings with medical professionals with whom they exchange information, raise doubts and issues, and request funding and collaboration. Nowadays, many of these doubts are resolved through other channels, like online forums, social networks or applications, such as WhatsApp. Associations like Ascatsk, Alejandra Grandes, a.m.a.r., the Spanish Association of CAH, are very active on Whatsapp which is, in fact, their most immediate and effective method of providing support through which they exchange lots of information. H-Hipos remarked that, while the incidence of hypospadias is very high and boys from Barcelona have made many attempts to find each other, even through a forum, it hasn't been successful: "There is only a Facebook group for hypospadias. It's very interesting. There are many mothers in there. There is a great demand on mothers. The mothers don't know what to do. They don't know if they'll need to operate or when".

The associations that were studied sustain themselves fundamentally through the voluntary work of their members and are self-financed by membership fees and limited funds from health centres, programmes and foundations. The same problem is seen in FECAMM (the Catalan Federation for Rare Diseases) and FEDER (the Spanish Federation for Rare Diseases), both of which are key institutions providing resources and support to these associations. Problems related to the self-governance of the Catalan Federation, which is comprised of twenty different associations, were highlighted by P-FCMPF in that, although they receive some funds from the Department of Health, Barcelona City Council, the regional government and Social Welfare, these funds do not cover all of the needs that are not guaranteed by the public Administration for the individuals concerned. Among the many procedures they offer, they help to establish partnership agreements with companies to handle, for example, legal and judicial consultations (judgements, disabilities, etc.), social care and physiotherapy services, assisting people in their homes for a low fee. There is a high number of needs and requests. For example, the following request was made by the Catalan Association of Klinefelter Syndrome:

> As an association, we need a place where we can hold meetings and assemblies. It doesn't need to be permanent, or big, or have any specific audiovisual facilities, just a room where we can meet with ease, on a couple of Saturday afternoons each year. One medium-term objective that we would like to achieve is to hold an outreach session with one or more health professionals, who can explain and quell doubts raised by affected individuals and their relatives, con-

> cerning the level of knowledge about this syndrome. In this respect, we're seeking assistance to find a place that we can use to achieve this and perhaps financial contributions to help cover the costs [Email sent by the Ascatsk association]

P-Turner2 reinforced the issue of funding, which is needed, for example, to be able to make more subsidies or grants available for rehabilitation, to create and maintain online information or to organise open days and participative activities. But, above all, he wanted to raise awareness of the truly fundamental support function that associations provide to patients, "with goodwill they can do so much" // "They understand our situation". In general, financial support and/or resources are required to "design visibility and normalisation campaigns", to design projects, for example, for labour market inclusion —to open effective channels with employment departments— aid, grants or subsidies for jobs within the association and for it to be able to manage itself, to open doors to schools or to create networks and links between organisations. GrApSIA, which has become an accredited intersex association both inside and outside of Spain (due to the media, professional interest in intersex people and as the recipient of individuals with all types of DSD), reiterates how difficult it is for its member volunteers to meet this demand. For this reason, they mentioned that it would be of great help to have someone to fulfil the role of secretary to respond to emails, request grants, organise awareness events, campaigns and workshops.

Throughout this study, and precisely because of it, our interviewees have become aware of other intersex variations/DSD, while making contact with people from other associations. Through meeting each other, they have discovered shared problems and needs. This has sown doubt about the best way for associations to organise themselves in order to be more effective. Some medical professionals think that it would be a positive thing to create a bigger association which covers all DSD. D-FEDER gave the example of an association that caters for different pathological conditions with a shared common problem: the Spanish Pudendal Neuralgia Association. This association welcomes different conditions which share a symptom: the presence of pain when sitting, during sexual relations, and when carrying out physiological needs. This example serves as a pretext for some of the interviewees to think about the possibilities for intersex/DSD associations.

Educating in diversity. The dualism of dualities

The majority of interviewees agree that employing education and awareness as a means of rooting out discrimination directed at people with intersex variations or DSD, is the same as the strategy applied by trans, lesbian and gay movements. It is about educating people about diversity, breaking away from the idea that the body, gender, identity and sexuality can be classified according to the ideal binary model of man/woman, masculine/feminine. It consists of making people aware of the idea of continuity and the idea that specific outward physical characteristics do not necessarily coincide with the precise identity of a person, nor their actual desire or sexuality. For example, both socially and medically, XY chromosomes are attributed to having testes, a penis, and a scrotum of a specific size and shape, an outward masculine appearance, male behaviour, the identity of a man and a heterosexual desire for women. The same theory is applied to people with XX chromosomes; ovaries, uterus, vagina, female genitalia, the identity of a woman and a heterosexual desire for men. This education would consist of breaking down this idea of gender coherence, and in some cases, even tolerating fluidity, non-dichotomous and “middle of the road” options. Gender education is a key mechanism in dismantling this idea of coherence, in order to accept and learn about new ways of experiencing and viewing the body, identity and desire.

> I think it is very smart for everyone to question their gender stereotypes. Throughout life we’ve had this instilled in us, sexuality, the security we feel when we have an emotional relationship with another person. Everything. But that’s why I wouldn’t just approach it from the LGTBI perspective, but rather the whole of society in general. I work with a team of psychologists, sexologists, and on a daily basis we see it in non-LGTBI populations, the concept of gender stereotypes in the cissexual population. How my genitals should look, how I should behave, that something is masculine, that that’s a boy or a girl. We have to question all of that. // It’s a task that has more to do with how our society as a whole only recognises stereotypes corresponding to two genders, and to realise that, at best, we could speak of a third option, somewhere between the two ends of the spectrum, or even, that the binary utopia doesn’t exist at all. We are all intermediary, and that is what we need to focus on. Our assessment criteria should be based on our self-esteem. // I didn’t approach this from a strict LGTBI point of view, I approached it from the view that our society as a whole needs to question all of the gender stereotypes. If we see it like the LGTBI do, great, because clearly, a transsexual person is the first to question it, because life imposes these stereotypes on us from the word go. But there are people who neither identify as trans, nor simply as homosexual, who also question gender stereotypes every day. And it’s good that they do that, because stereotypes do us a lot of harm: guys have to be aggressive, “I don’t want to fight with anyone”, or women have to be seductive and charming, but why? (H-inter).

All of that must be integrated into education, in schools, colleges, in editorials, in continuous teacher training centres. P-Grap tells of how school is a reflection of society. Books continue to polarise biology in the face of history and there's no room for diversity. This is why they propose ways of achieving it: "educating through positive values and appreciating and celebrating our differences"; running awareness campaigns with workshops, with students in schools, via television adverts, etc. Regarding the teaching material that could be used, different initiatives have been suggested, although the use of audiovisual material is considered particularly useful. During the interviews, the following audiovisual documentaries were mentioned; *Me, my sex and I, XXY, Orchids, My Intersex Adventure, What it's like to be intersex, Is anatomy destiny?* (TED Talk by Alice Dreger) and *Nobody is shameful:*

> In the video *Nobody is shameful,*, various intersex people talk for around three minutes. You can sense the difficult and strong emotions, though. It's fine. But, it is what you say; speak in this way, with a happier tone. It is not necessary to minimise the negative effects, but I think it is important that when a person stands up for something, especially when communicating something unknown, it's better to leave a positive mark. After many years of not feeling normal, psychology, and later sexology, helped me to accept my body and to be satisfied with what I have, to talk more positively about it, and mostly, to not complain. Emotions need to be positive, because we've seen enough negativity (H-Hipos).

The creation of positive information is called for, “because I had to wait twenty years to tell my friends about it. If you react with embarrassment, so will they...”, and “brave” initiatives are also valuable in breaking down stigma. “There is a person called Hiker Chiu who gives *intersex* hugs. He goes to universities and schools and talks about intersex in a very cool way. He’s on his own, but look, he has balls. I think it will open up the minds of a lot of people. He made his own activism” (H-Klinefelter). They also insist on the need to adapt cultural values and beliefs in order to change one’s own self-image and self-worth:

> It is essential for assertiveness. First there is the value of “me as I am”, your concept of yourself. Then, “this is how my genitals are, how do I value that?” Later on, we arrive at the issue of self-esteem. There are three levels: self-image, self-esteem and assertiveness. What concept do I have of myself and my genitals. My genitals are not, let’s say, standard. I give them definition. In principle, it’s a neutral definition, but they become loaded with significance if I introduce an assessment criteria to define whether these genitals are good, bad, or normal. And it’s always a social criteria, because we take on board all of the information available; that is how social learning works. // So that, for me to value the fact that I’m homosexual, first I start from the context that I operate within, and, if they say that being gay is bad, I will believe that it is bad and I will internalise homophobia. If I consider that having ambiguous genitalia is shameful because that is what those around me think, I will internalise that. So, if I regard my genitals as shameful, will I show them to anyone? Will I have sexual relations? Will I be able to expose my body? No. It’s unthinkable. / What’s the first thing that needs to be done? Change these assessment criteria with regard to the traits you are composed of. And with regard to gender, what they are doing is very interesting in this sense (H-inter).

CHAPTER II

INTERSEX IN THE FRAMEWORK OF EUROPEAN AND INTERNATIONAL HUMAN AND SEXUAL RIGHTS POLICIES

While the first phase in the international activism of *intersex* communities focused on transforming the medical approach to intersex conditions, and stood out for condemning the *status quo* of medical treatments, and for trying to re-educate and establish alliances with medical staff, the latest phase has forced these changes to be implemented from a legal perspective, based on human, sexual and/or patient-client rights. The legal field has created platforms from which to monitor and regulate decisions made by parents and doctors, to protect children in the decision-making process, to report abuse and request comprehensive information or informed consent. These changes have opened the door to some new experts: lawyers.

Decision making was transferred to courts, and lawyers and judges became external experts who started making decisions based on the evidence presented and also by applying personal judgement —experiences, values and beliefs—. The management of intersex in the legal sector was settled upon for the first time in the Supreme Court of Colombia in 1995.

Often, the struggles against discrimination and prejudice suffered by intersex people have been included on the agendas of the LGTB community. In May 2014, the commissioner for human rights from the European Council, Mils Muižnieks, published a paper *A boy or a girl or a person — intersex people lack recognition in Europe*, which outlines the changes made to human rights which were secured by intersex people. The paper informed governments and experts about the development of a human rights ethical framework. Allegations made within the legal framework of human rights have been based on the following items:

Non-consensual surgery:

"Corrective" surgery and treatments that aim to aesthetically "restore" the gender of babies are explicitly condemned. It is thought that these can result in an irreversible gender assignment and sterilisation, without consent from the individuals concerned. They are also viewed as traumatic and humiliating procedures, rife with short and long-term complications, which can be physical and/or psychological. In addition, a frequently reported complaint is the fact that medical services are hardly ever transparent with their statistics and case management, and that patients have difficulties accessing their medical records (Heinrich Boll Foundation, 2013).

Regarding informed consent, it has been suggested that individuals themselves should decide whether or not to have "elective surgery" (surgery performed on psychosocial grounds, and which, if not performed, would pose no danger to the patient's health). It calls for patients to be guaranteed the necessary time to carefully assess the risks and benefits of the procedure and to identify what is the most suitable choice. The new law (*Gender Identity, Gender Expression and Sex Characteristics Act* —GIGESC—) of Malta, which was recently approved in April 2015, is the first law anywhere in the world that prohibits the performance of surgical procedures on intersex people that are not a medical necessity; that is to say, all cosmetic surgery in children that is the result of social expectations imposed by the binary gender-sex model. Articles 14.1 and 14.2 of this new law states:

> 14.1) It shall be unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention can be deferred until the person to be treated can provide informed consent:
> 14.2) In exceptional circumstances treatment may be effected once agreement is reached between the interdisciplinary team and the persons exercising parental authority or tutor of the minor who is still unable to provide consent. For as long as the medical procedure is driven by social factors without the consent of the minor, it will be in violation of this Act.

The right to self-determination and physical integrity:

It is considered that early elective surgery does not respect the right to self-determination and physical integrity because babies and young children are not in a position to give their consent. The United Nations Special Rapporteur on Torture (2013), appeals for any law to be rejected that allows intrusive and irreversible treatments, including genital normalisation surgery performed without the free and informed consent of the people concerned. This stance is shared by other institutions and nations, such as the Swiss National Advisory Commission on Biomedical Ethics (2012), which appealed for surgical procedures performed for sociocultural reasons to be eradicated.

The proliferation of reports on *intersex* issues from national medical ethics committees has spread awareness of this approach. The United Nations Inter-Agency's recent adoption of a position in response to sterilisation is viewed as a milestone in the merging of medical and human rights approaches. This report also includes the violation of intersex persons' physical integrity.

Vignette by Kate Bornstein (1994)

Information and support:

In 2013, the Parliamentary Assembly of the Council of Europe insisted on the need to provide appropriate advice and support to children, parents and families. It argues that this provision of information and services, as well as being the responsibility of medical or psychosocial professionals, should also involve intersex people and civil society. It is at this point that it calls for the need to improve training in health and social services regarding intersex issues and their implications on human rights.

Legal recognition:

Birth certificates and other official documentation almost always require a person's gender to be identified in binary terms. It has been reported that people without a clearly identifiable sex have to cope from birth with the fact that they are placed in identity limbo (See the following section for information on new legislation to promote legal recognition).

Promoting awareness and reforming legislation:

Legislative reforms are seen as necessary tools to achieve the equality of intersex people. These reforms should raise awareness about the standing of these people in society, as well as the discrimination and prejudice that they endure on a daily basis, even as adults. In 2013, the Australian Parliament introduced *intersex status* among other fields protected from discrimination. It is believed that an urgent review of medical practices and current laws is needed to identify gaps in the protection of these people and take measures to address these problems. It has also been suggested that this review should involve organisations such as the OII Europe and ILGA-Europe, who work to defend the human rights of intersex people and who have a long political history in this area. In fact, the OII Australia is the organisation that created the intersex flag in July 2013 for those intersex people that needed some form of symbolism. This flag was an attempt to create something that was not derived from other symbols, and at the same time steering away from colours, such as the pink and blue of other flags. Morgan Carpenter, of the OII Australia, explains it this way: “The circle is unbroken and unadorned, symbolising wholeness and completeness, and our potentialities. We are still fighting for bodily autonomy and genital integrity, and this symbolises the right to be who and how we want to be”.

Legal considerations

More recent decisions settled by the courts are not free from controversy and reflections: in Australia —in March 2010, thanks to the case of Norrie May-Welby— a third gender option was included in birth certificates and passports, "indeterminate" or "sex not specified". Also in Germany, since November 2013, you can leave it blank or select man or woman on birth certificates; and the same in France, where a person can also be recognised as gender neutral. With respect to German law, although in principle we find ourselves at the forefront of a progressive law that provides legal recognition, it is argued that it leaves intersex people and their families in a very vulnerable position. First of all, to speak of an indeterminate sex presupposes the existence of a particular sex; it reverts to putting distance between the normal and the abnormal and, therefore, belief in the naturalness of duality is maintained. Furthermore, the party with legal standing to classify a baby as one of the three categories is a team of medical experts who determine how those born with ambiguous genitalia should be registered, since the law became effective —which means, in principle, and in the absence of judicial interpretation, that the register does not provide for changes to people born prior to 1 November 2013. Ultimately, this means that newborns are registered as X based on a report prepared by a medical team that regards them as abnormal (García-Dauder, 2014). Preves (1998) warned about the consequences of including an indeterminate category in background documentation. According to the author, since expectations are set by sex and gender in most social interactions, disabling this feature for people could be extremely problematic for them, socially.

For her part, the North American intersex activist, Hida Viloria (2013) argues that, although a step has been taken towards recognising the legal existence of intersex people, it has been implemented without taking into account that, in Germany, to enter into a marriage you have to be listed as a "woman" or a "man", and you can only get health insurance if you register using one of these two categories. Many people have voiced their belief that these issues should be taken into account before such a radical reform is implemented. Some associations, such as the Deutsche Gesellschaft für Transidentität und Intersexualität and Zwischengeschlecht, believe that the reforms in Germany will not prevent gender assignment surgery. They argue that, in response to the fear of indeterminacy, the parents of babies with genital ambiguity, in succumbing to the normalisation pressure, will opt for corrective surgery (García-Dauder, 2014).

According to Viloria (2013), with this new law, a new class of citizens who are denied equal rights and access to basic services has also been created, and they are being left without legal protection to respond to the abuse that their bodies are subjected to. For his part, Mauro Cabral, an Argentinian trans and intersex activist, says that it is important to distinguish between Germany and Australia: “Australian law allows adults to access an X in their identification while German law allows intersex newborns register as an undetermined sex”.

These kinds of reflections on the new intersex legislation and policies lead us to consider the concept of “intersectionality” (Crenshaw, 1989). Intersectionality has been used as a theoretical tool that allows you to describe the intersections between the different axes of domination and see how they work to reinforce each other. It also allows us to see the interrelation between the different forms of violence, sexism, racism, classism, discrimination for not using the dominant languages, specific discrimination due to disability, lesbophobia, homophobia, biphobia, transphobia, age discrimination, discrimination against minorities, Islamophobia, Christianophobia, rejection due to political ideas, etc. At the same time, it allows us to see how gender, ethnic origin, social class, (dis) ability, sexuality, age, minorities, political ideas or religious beliefs are interrelated, which prevent or encourage discrimination or multiple inequalities when health or political agendas are put forward. For this reason, we must ask ourselves where they stand or whether we're excluding people who have been diagnosed as intersex/with DSD when creating policies for people in social exclusion, gender equality or immigration and integration policies. In the same way, we should also ask ourselves who we are excluding or if we are leaving these people in a position of greater vulnerability when designing specific policies for this group. Nor should we forget, in a city as culturally diverse as Barcelona, about who we may be leaving out of this report because they do not have the basic conditions to participate in an associative movement.

INTERSEX/DSD INDIVIDUALS IN SPAIN'S LEGAL FRAMEWORK

We are witnessing ongoing legal changes in the field of intersex/DSD and major victories for the rights of the intersex community in European and international laws. We have already talked about the new legislation that prohibits the performance of surgical procedures on minors (in Malta and Chile, 2015) and about the new legal category, indefinite gender, available on official forms in Germany and Australia. Soon, we shall hear about new victories, probably in the world of sport.

In Spain, legislation on intersex issues has only just started, but in recent years we have seen intersex issues appearing timidly in virtually all of the LGTB policy legislation of the State. However, as a result of what has happened in the international legislation already mentioned, we believe that, before considering any radical changes, all of the pros and cons need to be thoroughly examined. After reviewing the latest legislation published and draft legislation that covers intersex issues in Spain, our conclusions are as follows.

Intersex individuals are currently taken into account in legislation in the regions of Madrid, Navarre, the Basque country, Galicia, Extremadura, Catalonia and the Balearic Islands.

Generally speaking, intersex issues have been included under the LGBT umbrella, so when the law speaks of any common aspects, it does so in the following way; "lesbian, gay, bisexual, trans and intersex people", without further nuances or prior chapters that specify which individual aspects or differences to bear in mind regarding people with intersex variations.

The Law on Gender Identity and Expression and Social Equality and Non-Discrimination of the Community of Madrid (March 2016)— the legislation that currently covers intersex issues in the most comprehensive way in Spain, and most recently in the Balearic Islands (May 2016), the latter of which is almost a copy of the Madrid law— is intended to guarantee comprehensive and adequate care for medical. psychological, legal, social, employment, and cultural needs. Detailed below are some of the points that it covers.

It specifies that, in the case of intersex people, and as a new feature, the present regulation guarantees the physical integrity of intersex children until they are able to define their own identity, and offers the protection of privacy and dignity against practices of exposure and analysis of an abusive nature. It also recognises that in attaining the protection of intersex people, the diversity of human bodies must be recognised, and the belief that there is only one regulatory standard for correction surgery must be eradicated. The reason for this is that it leads to intersex children being operated on during infancy to assimilate them to the standard of man or woman, without knowing which gender identity is actually felt by the intersex individual: "man, woman or simply intersex, any surgery that assimilates a child to a specific identity could result in a real and traumatic castration".

Despite this, we see that intersex continues to be identified primarily as a childhood problem, since the protection it provides is defined only in terms of early genital procedures and identity issues. In fact, we interpret a tendency to associate intersex people with a gender identity that does not conform to the normative standards.

The law also prohibits genital surgery which the affected person has not consented to or is not necessary to restore biological functionality for health reasons.

In article 8 ("Advisory services and support for transgender people, their families and people close-by") under heading I ("Administrative treatment of gender identity"), in section 4 it says that all services referred to in the present article will also specifically attend to intersex people.

Under heading II, "Healthcare for trans people", in article 15, "Healthcare for intersex people", it says:

1. The public health care system of Madrid must ensure the eradication of genital modification practices in babies which serve only to meet surgical standards, at a time when the real identity of the newborn intersex individual is unknown. With the exception of there being medical grounds to protect the infant's health and always with legal authorisation.

2. We must seek to retain the gonads in order to preserve the processes that will occur in the future that are not hormone-induced, including tumour markers in check-ups.

3. Hormone treatments must not be carried out for experimental purposes or otherwise, until that person or their legal guardian requests them based on the perceived sexual identity.

4. Genital examinations must be limited to what is strictly necessary and needed for health assessments.

5. Health workers need to be trained with a particular emphasis placed on politeness and privacy.

6. A patient's privacy must be preserved in their medical records to ensure their condition is not visible to all health workers who access their file, except in cases where it is strictly necessary.

A level of care in the field of sexual and reproductive health has also been proposed, with specific programmes that respond to the needs of each condition. In turn, it is considered that there is a need for research in assisted reproduction techniques and access to treatments that facilitate these individual's potential for fertility, whether now or in the future.

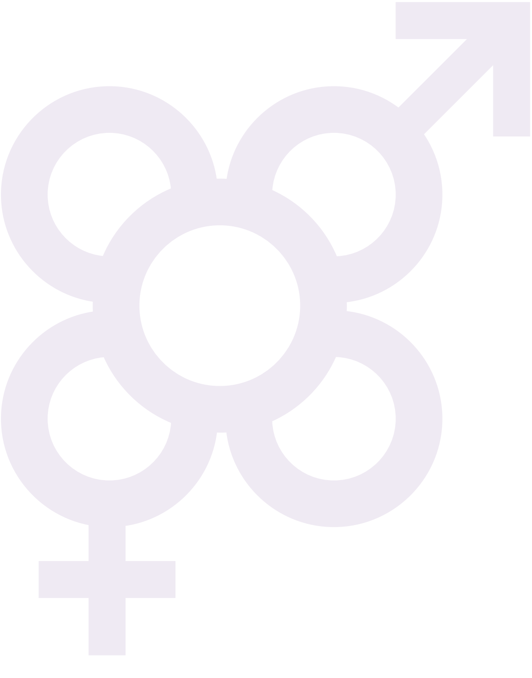
The dangers of polarisation and the single story

In carrying out this analysis we have identified various positions which are in direct opposition to the management of the intersex/DSD community. We can outline three different stances: on the one hand, there are people who defend surgery as a solution to problems, or the stigma aimed at people with atypical genitals. These people continue to evaluate gender identity, gender roles and sexual orientation in people diagnosed with DSD. This position is typically held by biomedical professionals. In an intermediary position are the professionals, parents and patients who trust in the need to work from the field of medicine, improving care procedures, working on bioethical issues and educating, and creating collaboration networks. Within this group are those who devote their efforts to working on stereotypes and gender bias, and those who do not put a lot of trust in options aside from elective surgery. Lastly, we found another group who allege that the issues threatening intersex people are clearly related to socio-political interests, cultural values and beliefs, composed of rigid concepts, such as gender assignment, sex/gender, masculine or feminine. From this point of view, only a legal or political solution can remedy the discrimination and lack of human and sexual rights of this community. In just a few years, the number of reports and publications about human rights, LGTBI activism, respect for corporal integrity and self-determination has increased. According to H-inter, we find the key to this conflict in the concept of "functionality", understood as the ability to function personally and socially. In that regard, he says:

> I would speak a lot about functionality. In other words, the doctor shouldn't consider something anomalous if it is functional. While genitals remain functional… it could be that you can't get this person to reproduce. But the aim is not for them to be fertile, but to have genitals with which they can achieve satisfying relationships. I believe that in this day and age, in the 21ST century, thanks to things we have worked on together, people being able to reproduce is pretty outdated. There are people that haven't considered having children, that can't have children, and they all lead very functional lives. I don't think that a person's objective should be to reproduce. // I would speak about functionality on a sexual level, on the level of affective communication, and so on. And evidently, on a urogenital level, of course. One of the things I considered about not correcting hypospadias as an adult, was that I would have problems urinating. In other words… There was one thing I did insist on, I said that I would be very happy to be able to pee standing. // Okay. I didn't go in the end. Because it's nonsense. I can pee quite happily sitting down. And then, every time I say that I pee sitting down, I come across 500 other people that do too, because of the prostate. And I say: well, that's cool. / These are things that happen, and there are people who think that they are very important, but they're not really. And when you question them, you start making them realise.

In this competition between "medical question-social issue", the complexity of the subject is often obscured, it hides the every day doctor-patient experiences in which positions are not so polarised, as well as the diversity of people and situations. In addition, it destroys the opportunity to attend to the health of these people from a true biopsychosocial perspective and the ability to create support networks. In Miguel Missé’s interview with Vincent Guillot, a French activist from OII *France* during his stay in Barcelona in 2009, Guillot considered the differences that exist between European and North-American activism. In the USA, it was the affected individuals themselves who denounced the medical practices and asked for changes. In Europe, intersex issues, became known and disseminated through an LGBT or queer academic and militant context. In this sense, Guillot admitted the difficulty in reconciling the intersex movement in Europe, considering that great differences exist between the movements of patients with intersex conditions/DSD —in which the majority of people with intersex conditions have sought a reference community— and the political intersex movements— in which the minority of people are intersex:

> Patient associations have existed for a long time, but each one works for its own "pathology" without ever calling people “intersex” or “hermaphrodites”. At the beginning of the 21st century, the intersex movement emerged in Europe in the shape of a feminist/political movement. Since then, it has been in a constant state of evolution. On the one hand, because everything needs to be invented (overcoming stigma, developing vocabulary, learning how to get to know and accept oneself beyond the pathology), and on the other hand, because the founders of the movement, feminist/political militants, were not sufficiently aware that all emerging movements must build themselves up (the need to create a name for themselves, make complaints) before addressing political struggles. Currently, there is a misalignment between the historical militants and the intersex community who still want to explain and find themselves amongst each other (Missé, 2009).



Certainly, the presence of people with intersex variations/DSD within the LGBT communities is rare or occasional, and confrontation between LGTB political activism and medical discourse is constant. PSGs would be located in an intermediary position, showing more of a tendency towards medical discourse, with unquestionable alliances with medical professionals and the centres that address these issues. Some doctors are reluctant to abandon their prestigious and powerful positions, to accept their limitations and to accept that medical knowledge and practices can only address part of the problems. Since the 1990s, medical bodies have been heavily criticised, with condemnation of "normalisation surgery", and medical groups have tried to incorporate publications from Peer Support Groups (PSGs) about different conditions into their meetings. Today, the accusations are defended using the argument that they no longer work with their backs to the patients, and that they incorporate their viewpoints and assessments. Nevertheless, we must bear in mind that only a small portion of people diagnosed end up being part of a PSG. We wonder what the profile of people is like who do not work or cooperate with medical bodies or PSGs. Those people who have never come to patient or activist groups. Those who have found answers and ways of understanding away from the medical model, whether through other types of treatment, other forms of self-awareness, or through the understanding of gender provided by gender and LGTB theories. At the other end of the scale, we found reports like the one published by the Council of Europe Commissioner for Human Rights, *Intersex and Human Rights and Intersex People* (2015); a report which does not include people with DSD who only seek solutions in the medical field. None of these stances take into consideration the totality, and even less so, the heterogeneity of backgrounds, experiences and alignments.

The LGBT-I discourse about intersex leads to upset in medical teams and in many PSGs. People from the Catalan Ascatsk association explained that they do not feel included or addressed under the DSD umbrella, and far less under that of intersex. The connotations of the term “inter-sex”, “a half-way sex”, with echoes of homosexuality and/or non-prescriptive sexualities, fuels intense rejection. Without a doubt, these reverberations are fraught with homophobia and transphobia, but in any case, they do not represent a group which feels threatened under these acronyms and prefers not to be included in these policies, and would rather be covered by health policies catering to rare diseases . These groups have their own health demands. Meanwhile, biomedical language and medical and surgical solutions are rejected by the LGTB movement.

For example, although the proposal not to assign a gender to people born with intersex variations until they can decide for themselves in the future was well received by some intersex activists and LGTBI groups, it is also a stereotype that circulates around this associative network. In fact, one of the requests described in the third International Intersex Forum (Malta, 2013) and also by the ILGA Europe,—institutions that are central today to the defence of human and sexual rights and the intersex community— was the one about "registering intersex children as women or men, being aware that, like other people, they could identify with a different gender or sex when they grow up". As discussed above, the creation of another box or simply waiting for these people to grow up and decide, could place them in a position of vulnerability and expose them to greater discrimination. Thus, when Kate Bornstein responds to the question “is it boy or girl?” with, “We do not know. He/she still hasn’t told us”, it points out an interesting theoretical and political reflection of social transformation, but it does not mean that intersex people have to embody this position. Leaving someone without an assigned gender in a society where gender is the main social structure could also be considered a form of violence. An alternative could be to remove the administrative procedures around sex changes and remove gender as an obligatory field in all official documentation (like race and religion).

During a discussion between Med. Fam1 and Gin.Sex1, the former insisted on the need to avoid the unnecessary medicalisation of bodies. He meant that he found it difficult to understand why testosterone is still so necessary, and that it is the one and only solution. Gin.Sex1 interjected, arguing that, if he thinks that way, it is because he has not understood what identity is, testosterone doesn’t affect the body, but rather the identity, and facilitates the ability to be what one is. It could be that, in terms of confrontation, the problem is proposing this dilemma. Perhaps we should separate the two plans, the desirables —the assessment of our reality, the pressures and the abuse of gender and ideals—, and the vital needs of the here and now, the things that enable us to live in the world we live in. Regardless of whether we work in the direction of education on sexual diversity, to accept more bodies and identities (in which a woman with a penis can be and feel good, for example), for the time being, it depends on the cards we are dealt or the resources we have, a lot of people ask for "medicine" and "surgery" to mitigate the abuse in our environment. This is why is makes sense to take testosterone to be recognised by others (by oneself) as a normal, typical man.

We warn about the danger of a single story. Radically opposed stances invalidate each other and even vilify the proposals that do not conform to their own stance. The most medicalised stances denounce the interference of academia and politics in the life of people with intersex variations/DSD, and on the other hand, the discourses that speaks from human experience hide the people who opt for biomedical approaches and identify with them. The following table outlines the main dangers of this polarisation, as well as the aspects in which they differ.

LGTB(I)	MEDICAL CONSENSUS
Nomenclature: (intersex)	Nomenclature: (DSD – Differences of Sex Development, Disorders of Sex Development)
Standardise experiences Disregard the views of non-activists (e.g.PSGs) and the unheard people	Standardise experiences Take for granted that there are no people with intersex variations/DSD in LGTB(I) movements
Exclusion of any experiences that do not conform to the political discourse (the belief that the intersex community is wholly represented)	Exclusion of any experiences that do not assimilate with medical discourse or medicalisation (the belief that the experience of all of the people with DSD is represented by their patient collaborators)
Belief in the stagnation of the medical stances and practices outlined in the "Money model" (without changes or nuances)	The belief that the "Money model" is outdated and that the "Chicago Consensus" is the ideal model (there are only structural issues with the system: Non-existent/inoperative MDTs and isolated psychological support)
The absence of specificity for each condition in their proposals. Discourse centred around sex/gender assignment and surgical procedures performed on babies.	Pathologisation of identities and lives that are non-normative in terms of gender (research in gender monitoring and control —e.g. the controversial research in dexamethasone in CAH)
Sociocultural and gender focus	Medical-surgical focus with personalised psychological care

LGTB(I)	MEDICAL CONSENSUS
Disregard cases which have medical and/or surgical needs	Absence of non-clinical approaches in attending to the needs of people with intersex variations/DSD and their families
Denies the positive effects of normalisation surgery in some people	Denies the traumatic effects of medical procedures (examinations, surgery)
Makes generalisations with regard to “no procedures while there is no consent of the person", without qualifying the type of procedures and the potential health risks of not carrying out a specific surgical procedure	Does not accept the uncertainty of biomedical practices and research (e.g gonadectomies)
Lacks recognition for those who choose surgery (adults)	No openness towards other models of sexuality (sexuality based on relationships which include intercourse)
Assumes an intersex identity based on a non-standard anatomy	Non-acceptance of non-binary gender fluidity or gender expression
Undervalues biomedical research (e.g. new surgical technologies)	Undervalues psychosocial research (e.g. diversity, the social construction of science)
Obscures positive medical contributions	Obscures or does not give legitimacy to contributions of activists or social sciences

Gender policing

One of the issues that causes parents to worry the most is how to handle their children's atypical gender behaviour. Gender policing is more intense or even aggressive for those who do not physically conform with the norms. A paediatric psychiatrist said that when this happens, children become angry, reserved, depressed, they become withdrawn or shut themselves away in their rooms to play in secret, or they have suicidal thoughts. Upon reaching adolescence, these young people who have experienced high levels of parental pressure in relation to their gender report significantly higher levels of depression than those who have not suffered from this pressure, illegal drug consumption, suicide attempts or the practice of unsafe sex.

In the case of some syndromes such as KS, studies show a tendency toward the consumption of toxic substances like alcohol and marijuana as a personality trait of the disorder itself. Nevertheless, we have not found any studies about the psychosocial triggers that could lead to this consumption. H-Hipos reported that: "I know a lot of people diagnosed with hypospadias who started to drink, take drugs and medicate with anxiolytics because of this secrecy. Of feeling bad about yourself, of this shame. What do you do? You drink to forget, you get drugged up to forget… Because it's a massive burden" (H-Hipos).

To prevent this gender policing, it is proposed that guides, information and training are provided for parents of children with intersex variations/DSD, the same type as those made for parents of children who have non-normative gender behaviour. In this regard, there are plenty of initiatives and materials in the LGBT and coeducation sector. To cite an international example, we found a program guide, *Outreach Program for Children with Gender-Variant Behaviors and their Families*, which provides very useful information for parents frightened by the behaviour of their son or daughter.[ix] The guide answers essential questions —how can I help my son or daughter?— and offers simple recommendations of the kind: love your daughter or son as they are, question traditional presumptions, create a space where the child feels safe, encourage activities that benefit social acceptance, make your daughter or son feel valued, look for resources and support, talk with other important people in your life, prepare your daughter or son to face abuse from their peers or, anticipate problems and look to actively prevent them. The guide also warns of the pitfalls that they need to avoid falling into, such as provoking blame, pressuring them to change, etc. It also looks compassionately on parents, and tries to help them manage their own feelings.

The right time for surgery, the decision-making process and informed consent

Although the medical professionals we talked to prefer to support the International consensus guidelines of 2006, they also assured us that they do not agree on when to defer genital surgery, and claim that there is no consensus or clear guidelines about it. A paediatric endocrinologist explained that, although there is a tendency to operate in the first year of life, the patterns that mark the current paradigm shift and which are, without a doubt, influenced by the activist movement defending children's rights, sexual and reproductive rights and those that defend the patient, are generating controversies:

> Much has changed in the approach to treating bodies. They are still in the 19th century, if not the middle ages, right? // For example, about recent hyperplasia surgery, and coming from big cities, they say: "We'll operate when they're older" and we've operated on them at 10 and 12 years of age. // This, nowadays, has no justification. "The surgeon told us that they'll do it when we're bigger". No. // Nowadays, you have information everywhere. On the phone ... you're looking , and you have to read a little and "bloody hell, how is it that here it says that they are already doing it before they're one and a half or two years old?" (Cap. CirPed.Hosp4.).

Cap.Hosp1 also considers it a mistake, even cruelty, to condemn girls with CAH to rejection throughout their childhood due to the appearance of their genitals, so that they can make their own decision when they reach adulthood. The researcher pointed out an issue to reflect upon and review, which is the fact that activists have systematically criticised feminising surgery and, in contrast, haven't said anything about masculinising ones. We are also prompted to reflect on the disparity between stances, which has even reached the point, in the care of transsexual children, of how a diagnosis should be made, being against or in favour of the psychological aspect, etc.

Psychologist and sexologist, H-Hipos, claimed that the subject of surgery is still, for the most part, invisible and lacks control, in such a way that the ability to monitor whether people are given all of the necessary and varied information is lost. Ma-Nr5 criticised surgical procedures, claiming that "they don't operate for health reasons, they operate to achieve normalisation.// We're talking about social normalisation, not medical. They shouldn't meddle in that". Regarding hypospadias treatment, H-Hipos stated that surgical repair is systematically recommended but little is known about what these men experience; their sexuality.On the few occasions that this has been evaluated, only coitus centred standards and scales were used:

> What the doctors say, that —without corrective surgery, there is no normal life"—, is false. // There are people who have suffered far more because of corrective surgery. Botched corrections, multiple procedures. It gets very complex here: when a person has had lots of operations. In certain cases, it's more complex than not having had any. What I mean is that, there is still a lack of visibility. On the subject of hypospadias, it is very important because there are so many cases. For example, in my case, I really encouraged myself to write things down on a human level, in the first person, to help these people to start a dialogue. To view it all more normally... not normally, but with less complication. It is complex, but it is not especially complicated.

> In scientific literature, the possibility of living without surgery disappeared. In the past, in 1860, it was possible. They said that there was a doctor who left about four children as they were. And these four children went on to have children too. That means that fertilisation was possible. There wasn't that difficulty. I have been to meetings with surgeons sometimes, I know that it's a business. And it's a very successful business. Because you arrange for a few children around six months of age to be operated on. And they say: "We've already overcome so much, we already know how to do this".

H-inter brings new scrutiny to the debate: the unclear boundaries between necessary and unnecessary procedures. In this regard, I will say that in many cases, "not intervening is already an intervention":

> I think that when we talk about unnecessary operations... The other day I was speaking to the mother of a boy born with hypospadias and some genital ambiguity. Obviously, in this case, to ensure that the testes were functional, it was necessary to construct a scrotum, to repair it and all that. So, here the procedure is necessary to ensure a quality of life for this child in the future. Because not intervening in this case is an intervention: I have already decided how my son's quality of life will be. And that is very important, isn't it? The legislation always speaks of banning unnecessary procedures or looking to avoid..., they always include the adjective "unnecessary". / And that is very important: to know how to distinguish between whether it is necessary or not. For example, in these cases it is important, because if the testicle remains in the abdomen, it is unclear if it will develop into a tumour or not. / But malignancy is one thing, and making it functional is another. Not only do the testes contribute to masculinisation and the development of secondary sexual characteristics, they contribute to a series of... Everything. Not intervening can mean that the testis does not work correctly. But, of course: "We perform a procedure, and at the same time, we make a gland stop working". Those are the cases in which...; if we want to save the testis, a necessary gland, we have to operate. We have to construct a scrotum, and to do so, we have to repair or move the urethral opening. I'm not saying that it comes out the tip and that the child can pee standing. It comes out between the base of the penis, where the scrotum is, with the testes descended, but that's another thing. Whether the child pees standing or sitting, it's another story. The issue is with saving the testis. // Another type of case is "my little girl has an enlarged clitoris". Okay, but does that affect her in any way? Does it pose her a problem? No. So, that's it. But, it's big? So, what?
>
> If the child is born and grows up feeling like their body is normal, they won't be insecure about sexual relations when they have them. "It's about whether I'm normal, isn't it?" Just like there are big and small breasts, there are big and small clitorises. In this case, surgical intervention shouldn't be necessary. It is a matter of aesthetics.

P-CAH pointed out a problem with the lack of information from the doctors about other possibilities or alternatives to surgery. According to the mother, they don't explain to the parents or adults "that you can choose to not have an operation, that that possibility does exist". She recently appeared on a radio show about CAH in which they specifically spoke about this non-surgical alternative being offered (although she did not share which doctor had quoted it). When the women from the CAH group chatted about this interview via their Whatsapp group, they expressed surprise about not ever having thought that alternatives existed, in the same way that it surprised them that CAH was referred to as an intersex state.. They hadn't heard that before.

P-Grap considers the uncertainty of whether to legislate, and how to do so, in terms of banning surgical procedures. The GrApSIA spokesperson expressed doubts about the demand to leave genitals alone under any circumstances, on the justification that surgery reduced anxiety, or the unclear boundaries surrounding surgical procedures performed for health reasons. In any case, there is widespread demand from people with DSD and their parents for the health organisation in general, and hospitals in particular, to facilitate and regulate a free and informed decision-making process around any care procedures. In fact, in the field experience with debates between experts, patients and families, beyond confirming answers to questions like, "surgery in infancy: yes/no" or "removal of gonads: yes/no", they led us to decisive questions about the medical and social management of the variety of sexed bodies and to bioethical questions inherent in decision-making and informed consent.

The bioethical consideration seems inevitable with regard to parent's informed consent and the minor's right to sexual autonomy and physical integrity, which are "invalidated if irreversible surgery is performed". In the case of adult individuals, informed consent and free choice or autonomy to decide about their bodies prevail (García-Dauder, Gregory and Hurtado, 2015). However, they insist on creating the conditions for informed consent involving choice and psychological and emotional support for the "sufferers" and parents, focusing on the following aspects: the need for complete and comprehensible information, open communication, to receive information in favour of and against the recommended treatment, information about the risks and benefits that may result from the recommended treatment, information on other possible alternative treatments, including the rejection of treatment, information about the risks and benefits that can result from the other possible alternative treatments and the rejection of treatment and, above all, to be given enough time to make decisions.

There is open controversy about informed consent being provided by parents. Boyle, M., *et al.* (2005) stated that the information or advice is full of cultural constraints on what it means to be a man or a woman, what your normal social and sexual functioning is like, and full of assumptions about what genitals of both men and women are for. According to Dreger (2006), parents receive the message that the bodies of their babies are wrong or monstrous. In response to this realisation, Guillot (2008) claimed that although it apparently seems that they can decide freely, there really aren't any options to choose from. Many interviewees also concluded that parental decisions about early surgery in children with DSD depend on the information and advice received from the health professionals that take care of them:

> The precise issue would be, in the case of a child who is diagnosed with rather severe hypospadias, without any health problems, links, fistulas or whatever, how these parents who are directly told "operate" and they operate, and how these doctors would have the obligation to ... When there is informed consent, it means that you've given all the options, and that includes not operating. How to reach expert professionals so that they also have this information, and then they decide. Because these parents do not take this possibility into account: that the children choose. They believe that it is necessary (H-Hipos).

The need to find a way for medical professionals to have the obligation to advise about all of the alternatives, including non-surgical options, is reiterated. Although they may not place trust in, or do not have information about the experiences of people who are not involved, they should refer to people or groups where they can find references to other types of non-surgical experiences:

> It's due to ignorance and because there is also this idea that they possess the truth. But they don't, they should enable contact with the alternatives. They should be honest and say: "This is where we can get to and we can do this on a clinical level, but there are other alternatives". "There are other alternatives that we don't know about, but by calling this place, they can inform you". But, how do you start off that conversation? I don't know how to introduce it so that it becomes an obligation. Because now you are in the hands of people's good faith. At the moment, they are not being informed about anything else (M-Grap3).

> It helped me to know that other people go through this state. We have the same thing and we have to accept it. It's important to have these people to refer to, that have spoken about their intimate lives. For example, with the mother of a boy with hypospadias, we spoke about his intimate life, adults who have been operated on or not, etc. And mothers should be able to speak with these people to make a final decision on surgery (H-Hipos).

CHAPTER III

SOME INITIATIVES PUT INTO ACTION IN OTHER CONTEXTS

Strategies against stigma

The *Advocates for Informed Choice* (AIC) have developed a series of projects among which *The Interface Project* (TIP) stands out. This is a platform that aims to raise the profile of and broadcast videos that contain the testimonials of individuals with intersex conditions/ DSD, in addition to the nationwide project *Inter/Act*, a specific place for young people with intersex conditions/DSD between the age of 14-25 to express their individual needs. The idea of this project is to help adolescents to defend their rights, both during doctors visits and in their families, at school or university, in response to problems like bullying. The requests vary between the need to participate in PSGs, the need for honest and complete information about their diagnosis, the request for clear information that there are all kinds of alternative treatments and dignified care. We believe it's worth pausing to reflect on some of the requests expressed by those involved in this project, due to the clear connections we discovered with the Catalan context:

Support groups

- I need you to inform me about the support groups that exist. Being part of a community of men/women/ people with DSD truly gives me a sense of belonging.

- The doctor gave my parents a leaflet from a support group, but he advised them not to go to it because they were “crazy”.

- The association that I found with other men/women/people dedicated to these battles has really helped me to grow.

- The issue of mental health due to having DSD is more important than physical issues.

- My parents never spoke to anybody else, their silence affected my whole family.

- The support groups are great but that is just what they are: support! The only support that we cannot get from our doctors or families.

- Some of the best treatments I’ve had have been through support groups.

Revelations

- Be honest. Why don't you want to tell me something about myself? Why would you know about it if I don't? Honesty means that everything is not shameful.
- I already knew about it when I was seven years old, but my parents didn't think so.
- I wish I had known about all of this when I was thirteen, I would have started going to meetings immediately.
- My classmates started to experiment sexually, but I was fearful of my own body.
- I don't think that my parents knew that they had a choice.
- We are not fragile. Tell us the truth.

Communication and treatment

- Don't tell me that you knew how I will end up. My DSD doesn't mean that I will be gay/straight or that I identify as a boy/girl. Only talk about facts about my body.
- Don't lie to me.
- Don't lie to my parents.
- Don't speak to me in absolutes: "This vagina will never be enough to have marital relations".
- "If you know that I can't menstruate, don't ask me when my last period was".
- Don't take it as a given that I want a husband.
- Don't take it as a given that I am heterosexual.
- Know what you are talking about. We shouldn't have to educate the doctors.
- Don't try to convince me about how horrible it is to have a period.
- Please, tell me what's good about my condition. For example, not having to shave my armpits.
- Don't emphasise how rare this is.
- The doctors told me that they had never met someone like me, but it was a big turning point for me when I did.
- I wish my parents had access to therapy. They feel very alone.
- Don't ask me if I feel like a boy or a girl.
- Don't question me like I'm abnormal, or like something you've never seen before in your life.
- Don't ask small children if they have any questions when they are in a state of shock because of the genital examination you just carried out.
- Encourage us to write you an email. Encourage us to express ourselves. Drawings, writing, paintings… whatever it may be. Sometimes it's impossible to ask someone: "What happened to my clitoris?"

Surgery

- Don't tell a child that surgery is the only way that he/she will be able to have a "normal sex life with their wife/husband". Always offer a non-surgical solution. Surgery is the last option for everyone else. Why should it be any different for us?

- The surgery on my genitals ruins my self-esteem and confidence as a partner and a lover.

- It's painful that something is happening to you that you don't want.

- They operated on me in 1990, when I was three years old. I wish that they had given my parents other options. I'm sorry I have an enormous scar and it hurts that they didn't tell me that they had removed my gonads.

- There are moments when I think that, if they had been more realistic about the success of the surgery they wanted to perform on me, my parents would have warned me about the extent of what I wanted to do, and about doing it as quickly as I wanted. We all made mistakes.

- Don't tell us that only someone with a medical eye could notice the difference between a "normal" woman and us. It's devastating to find out that it's not true.

In the examination room

- Notify the nurses that will be working with me.

- Have a paediatric speculum to hand.

- Ask the patient how they want the examination to be performed.

- It's silly to think that an examination is not going to upset a child. Even adult women hate it.

- Treat the patients like experts on their own experiences.

- Don't protect us by speaking to our guardians rather than us.

- Don't invade the vagina of a young girl with your fingers if it's not required.

- A child can find it difficult to distinguish between a conventional genital examination and being touched inappropriately.

Recommended guides:

On an international scale, some groups/organisations or institutions have developed thorough and understandable, informative and psychological-educational material which is primarily available via the Internet —there is less available in paper format. To provide examples of these, we make reference to the guide with ten recommendations for carrying out vaginal dilations—*Top Ten Tips for Dilation (DSDfamilies)*—, and clinical guides directed at intersex individuals and health professionals. The most well-known are *The Clinical Guidelines* (2006), and other specific guides for the parents of children with intersex variations/DSD, *Handbook for parents* (2006) or *When your baby is born with genitals that look different... The first days* (2014). The first guide is based on the principle of "patient-centred treatment" and provides information ranging from all kinds of practical details for professionals, to scripts for talking with parents. There are other types of guides and stories published specifically for children and adolescents, such as a guide which tells children with CAH about their condition using language and a format adapted to their age —*A Girl 's Guide to CAH, by Emma* (2015) (Climb CAH Support Group, Living with CAH)—; and a German book explaining intersex in childhood —*Lila, Oder was ist intersexualitat?* (2009) (Intersexuelle Menschen) —; in Spanish *Pipo y Pepo, dos jóvenes exploradores* (GrApSIA), a story which helps to reduce anxiety in children in response to their gonads, during health centre visits and visits to medical specialists or in response to the possible need for surgery —orchiectomy—; and leaflets from *DSDteens.org*.

Warne and Hewitt (2012) offer a series of recommendations to help parents and healthcare professionals during this first phase, when there are atypical genitals and doubts about which gender to assign: for starters, professionals should try to avoid terms such as "him" or "her" and should refer to the newborn as "the baby." It is advised to minimise the psycho-social risks that result from exposing a baby with unusual genitalia, in other words, "restricting privacy until a correction of the external genitals has been realised" (ibid.). Among the recommendations, it specifies that nappy changing should be limited to one or two people, or that changing the nappy in front of siblings should be avoided.

Dreger (2006) is clear about what the recommendations should be for parents: "Remain calm" Wait until the shock has passed, until the feeling of suffocation disappears. Wait until you have digested the information, until you feel able to ask questions and speak with other people, especially with other parents or adults who have been through this situation. Wait until you have obtained more knowledge and feel prepared.

Guides for medical professionals

Broadly speaking, the demands expressed to medical experts in the 1990s are very similar to those that are nowadays set forth in the Catalan context:

1. Comprehensive and positive information.
2. Assign a gender.
3. Minimise medical examinations and exposure.
4. Provide images and use terminology which is depathologising.
5. Psychological support for parents and affected individuals.
6. Recognise intersex people as experts in their own conditions.
7. A moratorium on surgical procedures when they are performed without the patient's consent, or until medical professionals carry out comprehensive retrospective research on past treatments with results indicating that it is beneficial (Kipnis i Diamond, 1998).
8. Carry out long-term studies about the satisfaction and quality of life of patients (Preves, 1998).

According to Harmon-Smith (1998) the key to changing the experience for parents and patients is for doctors to avoid conveying the “notion of abnormality”. The medical perspective is the first to be received by parents, therefore, it is of utmost importance to ensure that these parents “do not feel ashamed of their children”. The author defined her proposal:

1. Do not tell the family not to name the child! It isolates them and they start to see their child as "abnormal".
2. Encourage them to give the child a name or a nickname (sweetie, pumpkin, buddy) or a unisex name.
3. Do not refer to the baby as “the baby”. That will make them see the child as an object, rather than a person.
4. Use the name chosen by the parents (even if it is “sweetie” or something else unusual).
5. Do not isolate the child in the neonatal unit because it frightens the parents and makes them think that there is something wrong with the infant. This isolates the family and prevents siblings, uncles, aunts, and grandparents from visiting and initiates a process within the family of treating the new member differently.

6. Allow the patient to be in a normal room. Allow other patients in the room or, at most, put them in an individual room with visitors allowed.

7. Put the family in contact with support services.

8. Do not prevent the family from accessing information from support groups. Do no presume that they will not understand or that it will be worse if they discover other conditions or related problems. Let the parents decide which information they would like or need. Encourage them to find other people outside of the hospital that may be able to give them information and share their experiences.

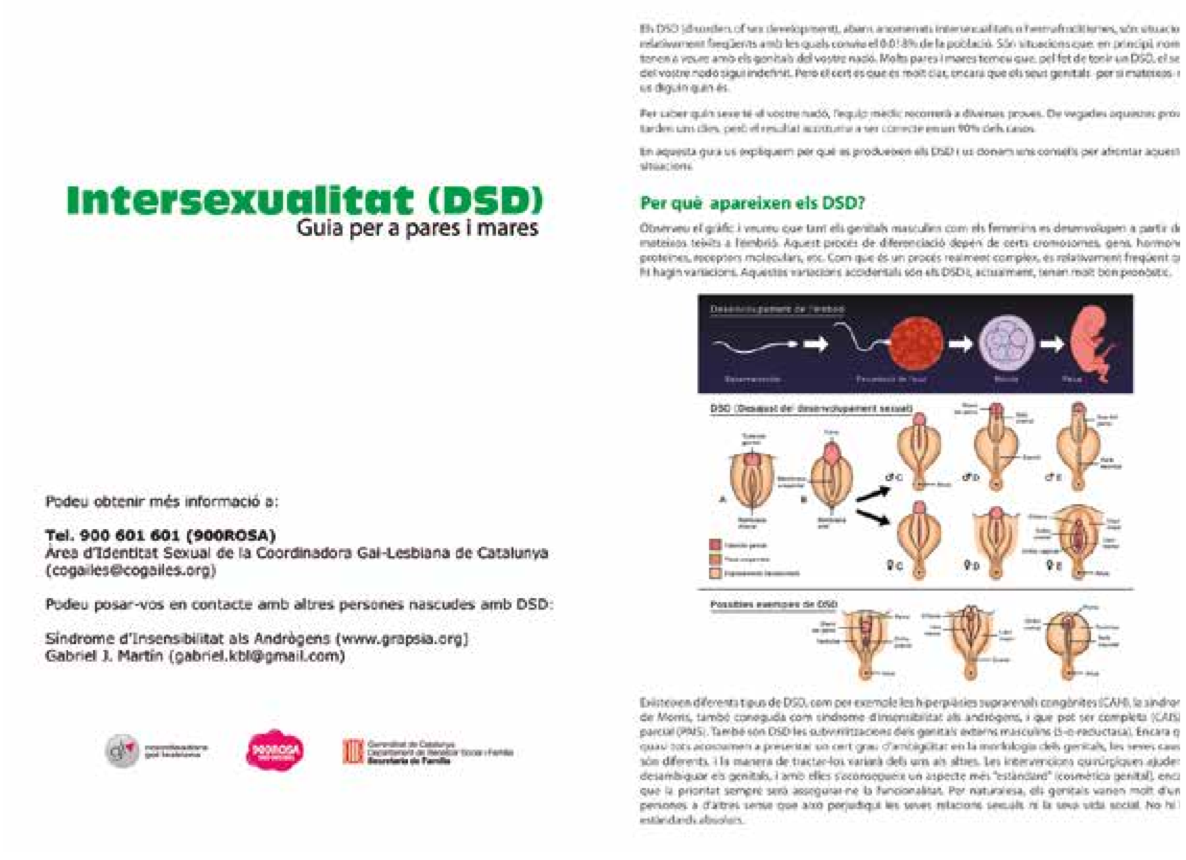
9. Encourage the family to find a counsellor or therapist. Do not refer them to a genetic counsellor, they need emotional support as much as genetic. Refer them to a counsellor, therapist or social worker with experience in family crisis intervention.

10. Do not make drastic decisions in the first year. Parents need to adapt to their child. They need time to understand the condition and its specific needs. Allow them to be present if there is new information or ideas. Allow them to understand that their child is not a disorder that has to adapt to a medical schedule, but rather that it is a person. Do not schedule the first surgery before the patient leaves the hospital. This will frighten the parents and make them think that they have an abnormal or defective child (Harmon-Smith, 1998, 371).

Handbook for Mothers/Fathers

The guide —*Handbook for parents* (2006)— provides condition-specific information, gives recommends to mothers and fathers about how they can speak with their sons and daughters and other people about the diagnosis, and it suggests resources where they can seek and obtain more information. The recently published guide, *Your beautiful child:*, by Viloria (2013). *Information for parents* aims to help parents overcome fear about their children's difference, but not just that, it also encourages them to see it as a feature to be celebrated, and to be proud of their children. Ellie Magritte from *DSDFamilies* has also been developing material with accurate information for parents, regarding what information to give and when to give it in terms of age. She is also designing a website with specific information for adolescence — *DSDteens*. Along the same lines, we found *DSD conversation through the lifecycle*, from the Klinefelter Syndrome Association, and other guides directed at adolescents by the AIC (Advocates for Informed Choice). In the case of GrApSIA, parents are calling for guides to be published which outline in detail the moment in which their daughters will be mature enough to understand their particular karyotype or the fact that their gonads are testes; how to explain this to them, or when and how they will be able to tell them that they will never have a period or will not be able to have biological children. These parents ask themselves when to give them this information, how their girls will turn out and if they will be happy.

Intersex psychologist and activist, Gabriel Martín, introduced the first guide on intersex conditions in Spain aimed at mothers and fathers —*Guia d'intersexualitat (DSD) per a pares i mares [Intersex (DSD) Guide for fathers and mothers]* — thanks to the Ministry of Family (Department of Social Welfare and Family Affairs) of the Generalitat, regional government of Catalonia. This guide has been a victory, as it explains to parents, among other things, how the process of sexual differentiation occurs —it recognises the process of sexual differentiation as being "very complex, it is relatively common that there are variations"— and when and how intersex variations appear, using simple language with illustrations that help to reduce these parents' anxiety in the face of expectations and fears. It employs the words intersex and DSD (disorders/differences of sex development). The guide reassures anxious parents about their baby's future, telling them that "although many mothers and fathers fear that, due to having DSD, the sex of their baby will never be defined, the truth is that it is very obvious, despite the fact that the genitals —on their own— do not tell us which it is". The guide also advised that these boys and girls will have a stable gender identity and that, in case there are doubts about the sex, medical tests can identify it in 90% of cases. This guide was introduced into hospitals in Catalonia, in all of the regional hospitals that have maternity and neonatal wards. Martín mentioned that many professionals had been in contact with him to request more.



Intersexualitat (DSD)
Guia per a pares i mares

Podeu obtenir més informació a:

Tel. 900 601 601 (900ROSA)
Àrea d'Identitat Sexual de la Coordinadora Gai-Lesbiana de Catalunya
(cogailes@cogailes.org)

Podeu posar-vos en contacte amb altres persones nascudes amb DSD:

Síndrome d'Insensibilitat als Andrògens (www.grapsia.org)
Gabriel J. Martín (gabriel.kbl@gmail.com)

Per què apareixen els DSD?

Intersex (DSD) Guide for fathers and mothers.

Informative guide to rights

Receiving information about fundamental rights, about the right to informed consent, the respect of privacy, being taught to formulate the right questions to help defend these rights, or helping parents to find sources of information to learn more about their children's condition can be a great help for those who receive a medical diagnosis which speaks of congenital anomalies and rare diseases. In fact, beyond legal protection, the fact that a person with an intersex variation/DSD is still considered as the subject of rights holds immense potential. No only is their “normal” recognised and legitimised before the rest of society, but it also helps these parents to change their own perspective of their children and to break away from family dynamics such as secrecy, blame or shame.

Information brochures stand out among the more effective efforts and strategies of the AIC which informs parents and people with intersex variations/DSD of a series of rights. The brochure *Know your Rights. A Handbook for Parents* introduces itself like this:

> Know your rights. Finding out your child has a DSD can be a confusing and overwhelming experience. We understand that, as a parent, you want to do your best to ensure that your child has the care and support that will enable them to grow up happy and healthy. We also understand that you want to make sure your child is receiving the best care possible. While the weight of this responsibility may be heavy, knowing your rights can lighten your load. This brochure is designed to give you a clear perspective on what rights you have when advocating for your child.

In general:

You have the right...

- » To receive considerate, respectful, and compassionate care regardless of your or your child's age, gender, race, national origin, religion, medical condition or disabilities;
- » To be treated as an equal in making decisions about your child's care;
- » To consideration for your personal beliefs and values;
- » To responses to your requests, needs, and concerns;
- » To request a language interpreter if necessary;
- » To ask for protective and advocacy services in cases of abuse or neglect.

The right to privacy:

You have the right...

- » To full consideration of privacy and confidentiality in care discussions, examinations, and treatments;
- » To expect that your child's condition should not be the subject of gossip and only discussed when necessary for treatment;
- » To accompany your child during examinations;
- » To know of the psychological consequences unnecessary examinations may have on your child;
- » To only allow examinations of your child that are necessary for treatment;
- » To limit persons present during examinations to only those individuals necessary for treatment;
- » To see or get a copy of your child's medical records and have the information explained to you.
- » The privacy of your child's medical records is protected by a federal law, the Health Insurance Portability and Accountability Act (HIPAA).
- » You may have additional rights protected by state law, professional guidelines, or regulatory agencies.

A contribution of the AIC and, in general, of all the organisations defending the rights of intersex individuals/people with DSD has been to show that there are options beyond the standard medical approach. That there are other alternatives, one of which is the refusal of medical treatment if a person's health is not at risk. True informed consent should guarantee this fundamental right.

You have the right...

- » To information that is complete and understandable;
- » To be told about the specific nature of your child's condition;
- » To be told why your doctor is recommending a specific treatment;
- » To be told of evidence supporting the recommended treatment;
- » To be told of evidence not supporting the recommended treatment;
- » To receive information about the possible risks and benefits resulting from the recommended treatment;
- » To be told about possible alternative treatments including non-treatment;
- » To receive information about the risks and benefits resulting from possible alternative forms of treatment and non-treatment;
- » To make decisions free from coercion and pressure; to have adequate time to make your decisions;
- » To be informed if your child's doctor is considering your child as part of a medical research program;
- » To decline to participate in or withdraw from a research project without fear that your child's care will be compromised;
- » To refuse treatment that is not in the best interests of your child.

You have options:

If you feel that your rights or your child's rights have not been respected, you can:

- » Speak to your child's doctor or nurse;
- » Request a consultation with a patient advocate or ethics committee;
- » Request a different doctor;
- » File a grievance with the hospital or with state or federal regulatory agencies'; Contact AIC for more information.

MAKING SPECIFIC PROPOSALS AND/OR RECOMMENDATIONS

If they ask us to broadly specify three priorities that we identified as the place to start acting, we would summarise them as follows:

1. Raise awareness of the experiences of people with intersex variations/DSD and those of their parents/families/caregivers.
2. Provide tools to facilitate joint decision-making processes between professionals and patients, as well as participation in health.
3. Raise the visibility and awareness of psychosocial needs and promote research from this perspective.

To finish, we will broadly summarise some of the proposals or requests expressed during this study.

Raising visibility and awareness

- Create campaigns to raise the visibility and awareness of intersex variations/DSD.
- Develop guides or information brochures.
- Observe Intersex Solidarity Day and create an events calendar around these dates (the Intersex Day of Remembrance was held on November 8, the birth date of Herculine Barbin in 1838. Nowadays, the Intersex Awareness Day has moved to the 26 October, so that educational and informational activities can last until 8 November).

In the field of patient care (in medical care or healthcare systems)

Rights

- Create specific public health policies for people with intersex variations/ DSD.

- The healthcare system should take into account the needs of people with differences of sex development, and guarantee the right to receive high quality medical care and profit from health services under equal conditions.

- Ensure access to comprehensive and high quality information —true informed consent— about hormonal treatments, assisted reproduction technologies, surgical procedures and sexual and reproductive health.

- Guarantee that both parents and adults have, at the very least, access to the most varied information that supports or does not support certain forms of treatment.

- Promote dignified and respectful health practices and psychological therapies regarding intersex variations, gender identity, sexual orientation and gender expression.

- Ensure integrated and adequate attention to medical, psychological, legal, social, cultural and employment needs.

- Prohibit genital surgery from being carried out on people with intersex variations/DSD when it is not required on the grounds of health, when it is only carried out to obey aesthetic norms, or when the decision is not made by the person affected. The proposal for “procedures only on health grounds” will sink in quicksand when it comes to establishing legislation (for example, gonadectomies or the removal of gonads due to the risk of malignancy when there are no conclusive studies available).

- Be adequately informed about these rights.

Health management

- Set up individual units (for example, for each geographical area or territory) where integrated and personalised care is available.
- Develop specific care programmes for intersex individuals / people with DSD.
- Facilitate the creation of MTDs in centres of reference, and the coordination of health services to make referrals to these centres.
- Encourage people with intersex variations/DSD and from the associations to participate in the decision-making processes of the MTDs.
- Encourage and promote people with intersex variations/DSD and from the associations to participate in health.
- Ensure that people with intersex variations/DSD take part in decisions related to the standardisation of new nomenclatures. The use of depathologised terms such as variations or differences are preferred over terms like conditions, abnormalities, disorders.
- Create a specific protocol for the birth of infants with atypical genitals with the consensus of medical and psychosocial experts and PSGs.
- Create and standardise alerts on computer programmes in the health service so that these patients are properly taken care of, such as alerts for CAH to know what to do in the event of an adrenal crisis (technological phase).
- Create and enhance IT resources to promote patients' self-care and to facilitate communication between professionals and patients.
- Implement a facilitator such as the case manager, liaison nurse or *patient navigator* to handle these situations. This facilitator will serve as a bridge to help people navigate through the maze of doctors, medical offices, clinics, hospitals, outpatient facilities, patient support organisations and other parts of the health system.
- To facilitate the channelling of patients or referral to expert healthcare centres.
- Streamline the specialist referral process and the process to change doctors, so that a proper diagnosis can be made as quickly as possible.
- Facilitate access to necessary medication free of cost (funding).

During consultations

- Avoid the repetitive and unnecessary exposure of genitals in front of a large group of doctors and medical students (to limit the number of people present to a maximum of two, that are known by the patient, and ensure permission is requested for anyone else to be present or for any new displays).

- Use language which is not sexist or pathologising, which welcomes diversity of experiences and that respects one's own identity and gender expression.

- Communicate the diagnosis from a positive perspective.

- Give families and people with DSD tools to handle the "clinical encounter", a moment that on many occasions is filled with nerves which decreases the ability to retain information. This material allows the patients, once they have returned to the calm of their homes, to re-read the information and prepare for the following consultation.

Research

- Guarantee the study and research of problems affecting the population with intersex variations/DSD and their families.

- Promote research into the quality of life in a way that takes into account the real and long-term experiences of people with intersex variations/ DSD (sexuality, happiness, etc.)

- Promote research into health in order to standardise treatment guidelines (high risk of gonadal malignancy, the age at which specific treatments should start, necessary and unnecessary treatments, treatment protocols, etc.)

- Promote research into the biopsychosocial health of people who have not undergone treatments or surgery (gonadectomies, vaginoplasties, HRT, etc.).

- Promote research into the psychosocial aspects of DSD.

- Promote research into assisted reproduction techniques, such as access to treatments to facilitate these individual's potential for fertility, either at present or in the future.(Cap.EndPed.Hosp1 explained that in KS, it has been demonstrated that extracting testicular tissue before puberty can make reproduction possible later on. Regarding individuals with TS, the possibility is being investigated of freezing eggs for future use (Ma-Turner). The possibility of cryopreservation of gonadal tissue which can be unfrozen and used in the future, has also been mentioned.)

- Promote and fund studies to evaluate and highlight methodological biases and/or the implicit heterosexism found in other studies on DSD (for example, studies on gonadal malignancy, models to evaluate behaviour and quality of life or the treatment of CAH with dexamethasone).

- Investigate, monitor and sanction studies that use experimental treatments, as well as the potential negative consequences they have on people exposed to the treatment (for example, the dexamethasone treatment given to pregnant women at risk of giving birth to a daughter with CAH).

Training

- Develop and facilitate the creation of recommendation guidelines for professionals, parents and adults.

- Formulate clinical best practice guidelines that include clear and easy-to-understand audiovisual material.

- Create ten best practice commandments. “A list of ten ethical and almost humanistic commandments. One for the City Council to approve which can then be taken to the Catalan Healthcare Institute so that it is complied with” (Gin.Sex1). Some proposals to include in this list would be:

    » Respect for physical integrity. No unnecessary procedures.

    » Protect emotional intimacy and health, by regulating and minimising the occasions on which genitalia is exposed.

    » Respect for one's own gender identity and expression, but without this having to conform with gender expectations or standard sexual bodies.

    » Offer care, support and alternative options, even if the patient's decision goes against professional recommendations and beliefs.

    » Offer true informed consent.

- Offer training to medical professionals in communication skills —so that they are able to easily explain terminology using drawings or diagrams, etc. —and about gender— to prevent the use of discriminatory and/or sexist language.

Measures for the field of education

- Sex and gender diversity education, to prevent harassment, discrimination and bullying.
- The regulation of information about sexual diversity in schools in all stages of infant, primary and secondary education (diverse sexual and reproductive anatomies rather than binary).
- Fund the development of educational material to facilitate the understanding of intersex variations/ DSD. Age appropriate material for children with DSD and also for the whole of society.
- Educate using positive values, appreciating and celebrating human differences.

Social-political-legal sphere

- Create a space for meetings and gatherings that associations and PSGs for people with intersex variations or DSD and their families, professionals and other parties can use to deliberate, voice their opinions and make suggestions about the rights, needs and requests of individuals with differences of sex development.
- Create a safe space where people from different disciplines can discuss opposing views.
- The creation of a working group involving intersex individuals/ people with DSD and psychosocial professionals (perhaps in the City Council) who participate in and advise together with MDT doctors.
- Create a protocol that directs medical professionals to refer their patients to these working groups and PSGs.
- Promote the creation of grants, bursaries or subsidies for the work carried out within the PSGs so they can be self-managed.
- Create a consultative and advisory body about intersex. This body should be able to guide and inform people about the subject, provide information about rights, suggest care improvements in public services and promote projects to raise the profile of and normalise this community in order to prevent discrimination.
- Create legislation to monitor, regulate and limit medical practices (also mentioned in relation to dexamethasone treatment).
- Set up an observatory from which to monitor and control any discriminatory practices directed towards this group in an institutional or employment context (obstacles were put in place for a woman with CAH in obtaining her driving licence, or in cases of KS and AIS, access to state bodies such as the Guàrdia Civil or Policia Nacional).
- Create a network of links between institutions, through effective channels with employment offices and schools, etc.
- Study the administrative possibilities of surrogacy for women with MRKH syndrome who would like to become mothers in the future.

Sport

- Be aware of the discrimination that arises in the world of sport directed towards individuals with differences of sex development.
- Reignite the historical memory of people with intersex variations who have suffered discrimination, harassment, violence and dismissal from top-level sport (for example, María José Martínez Patiño, dismissed from the Spanish team).
- Guarantee free participation without discrimination of intersex individuals/people with DSD in sport and in sporting competitions and ensure their correct treatment.
- Involve sports federations in the fight against this type of violence and discrimination so that they can prevent it and impose sanctions where necessary.
- Raise awareness among the general public to these forms of discrimination in the sporting world.
- Create best practice guides to educate sports clubs, associations and federations.

The media

- Create recommendations or best practice guides for the media about how individuals with intersex variations/DSD should be referred to.
- Ensure that media content is respectful to people with intersex variations.
- Train and advise the media about gender/sex equality and diversity.
- Follow-up on reports that do not respect gender/sex diversity and report them to the relevant bodies (the Ombudsman’s Office, parliament, the National LGTB Federation, etc...).[x]

CHAPTER IV

CONCLUSIONS

While it appears that the groups included under the intersex/DSD umbrella are unable to agree on what they should be called or how they should be categorised, we detected clear similarities regarding the problems, shortcomings and requirements in the areas of family, social life and in their pursuit of health and medical care. Discovering more common ground is difficult when people have a preconceived idea of what the notion of "intersex" is.

The fact that many people do not identify with the umbrella terms prevents them from constructing a community that is big enough and strong enough to fight common issues related to their own health and human and sexual rights issues. In performing this analysis, we have proved that, even though the word intersex is vague and annoying for many people with intersex variations/DSD who only understand it from a medical perspective, it has also opened up new possibilities. Ultimately, the preparation of this report itself turned out to be an educational experience and an opportunity to connect people with similar problems or organisations with similar associative objectives. In fact, it has awoken interest in understanding the connections between the inequality, violence and struggles encountered by the LGTB community and that of intersex individuals. The routine incorporation of the psycho-social field and education or training in sex/gender and sexual diversity, both in schools, for health professionals, and society in general, turned out to be one of the most common demands from our interviewees, in addition to an improvement in the medical care conditions for DSD individuals. The associative movement driven by individuals with intersex variations/DSD calls for financial aid for their self-management, actions to raise awareness about the issue and to educate the general public, to enable their contribution to health-related decisions alongside expert teams, as well as incorporating psycho-social and socio-cultural perspectives into care practices.

In conclusion, some of the policy objectives derived from this report should be:

- To guarantee the right to equality and non-discrimination on the grounds of differences of sex development

- Facilitate the participation and representation of these people and groups in all areas of social life.

- Promote the eradication of stereotypes and prejudices that affect the image of people with intersex variations/DSD.

With this report, Barcelona is putting itself forward as a pioneering city to guarantee these rights. As one interviewee remarked:

> We are talking about Barcelona, and that in Barcelona and its metropolitan area there are eight million people —and, although it is run by various councils, interaction exists. We are not talking about a small town. There is a large population and a lot of diversity here. I think that it is very interesting that large cities are equipped with these kinds of instruments, groups and centres. So that what is provided here can be provided in other places. Here, we can afford to create this, which is good for Barcelona, and is good for everyone, in fact (H-inter).

I. The author explains the enormous variability that hides behind this figure.

II. The association mainly caters for individuals and families with achondroplasia.

III. In Catalan, and in Catalonia where this study was performed, this would be translated as “anomalies o trastorns de la diferenciació sexual” (Audi Parera, *et al*., 2011). Nowadays, in response to the dissatisfaction of patients, especially of adults with DSD, it was decided that the wording “differences of sex development” would be used (3rd session about differences of sex development updates (DSD) (NOT CAH), 27 November 2015).

IV. Transcription symbols: / brief pause // long pause.

V. Refer to “Past experiences of adults with Disorders of Sex Development”, in Hiort and Ahmed (eds) (2014), *Understanding differences and disorders of Sex Development*, and “Tratamiento y afrontamiento del SIA: una tarea compartida” [Treating and dealing with AIS: a shared task] in *Rev Esp Endocrinol Pediatr* 2015;6 Suppl(2):28-34 | Doi.10.3266/RevEspEndocrinolPediatr.pre2015.Nov. 329 (http: //www. endocrinologiapediatrica.org/revistas/P 1-E17/P1-E17-S738-A329. pdf)

VI. This term has been used to refer to women with high levels of testosterone who have not been allowed to participate in competitive sports.

VII. A bioethical analysis of this controversy can be viewed at http://fetaldex.org/dex diaries.html.

VIII. Available at http://www.sindromedeklinefelter.es/documentacion/estudio-sameklin.

IX. The guide for parents can be downloaded via the following link: http://childrensnational.org/~/media/cnhs-site/files/departments/ gender-andsexuality-development-program/gvparentsbrochure.ashx?la=en.

X. Some of these recommendations have already been incorporated into Law 11/2014, to guarantee lesbian, gay, bisexual, transgender and intersex rights. Other have also been included in draft bills, such as the Law on Gender Identity and Expression and Social Equality and Non-Discrimination of the Community of Madrid.

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ANNEXES

INDEX OF ABBREVIATIONS

DSD	Differences of sex development
RD	Rare diseases
PSG	Peer Support Group
MAG	Mutual Aid Group
MDT	Multidisciplinary team
AIS	Androgen Insensitivity Syndrome
CAIS	Complete Androgen Insensitivity Syndrome
PAIS	Partial Androgen Insensitivity Syndrome
CAH	Congenital Adrenal Hyperplasia
MRKH	Mayer Rokitansky Küster Hauser Syndrome
TS	Turner Syndrome
KS	Klinefelter Syndrome
GrApSIA	Androgen Insensitivity and Related Syndromes Support Group
FEDER	Spanish Federation for Rare Diseases
FECAMM	Catalan Federation for Rare Diseases
ISNA	Intersex Society of North America
OII	Organisation Intersex International
HRT	Hormone Replacement Therapy
ART	Assisted reproductive technology
AIC	Advocates for Informed Choice

METHODOLOGICAL NOTES

The basic techniques underpinning this report are **gathering documentary evidence**, **in-depth interviews**, **participant observation** and **drifting** and **questionnaires**. The analysis performed was only qualitative in nature, because with such a small sample it was not our intention to seek statistical regularities, but to understand the different trajectories, experiences and narratives of the individual informants. We believe that this is the only way to access knowledge of the notions, representations, ideas, experiences and practices of these social actors.

In terms of methodological issues, we have to point out that these were the same as the limitations present in the topic of intersex/DSD: —the invisibility, silence and taboo—, in addition to the low incidence of these situations, all of this has considerably marked out the routes taken.

The interviews constituted a privileged way to obtain information. If there is something that defines the interviews that have been conducted in the course of this research, it is their diversity; that is why it has been necessary to adapt to each particular situation and be flexible with regard to communication style, formatting, and the time spent. The range of interviews used has fluctuated between spontaneous conversations, telephone interviews, Skype interviews and the in-depth interviews. The style of the interviews alternated between a formal and informal style, some interviews were more or less spontaneous, semi-structured or structured with a script, and the duration was between twenty minutes and four hours. Depending on the scenario in which the interview was carried out, they were either recorded, or in cases where we were in a rush or were lacking in time (for example, by taking advantage of people commuting to conduct the interview) or if there was a lot of ambient noise, we took notes and afterwards entered it all into a "memorandum". Informed consent was offered with the commitment to preserve the identity of the person interviewed, which was not required in all cases.

To avoid directing the interviews, in order to find out which aspects cause problems for each person or what they consider relevant or significant, our intention was to start each interview with an open question. The explanation of this research was, in many cases, an excuse and a reason to start talking, to provide certain information and not everything, and even to express dissent. If with this type of introduction we sensed a lot of confusion in the person being interviewed, we then opted to direct the questions a little more towards a semi-structured interview. This format enabled the individual participants to speak about things that are relevant to them.

One of the techniques employed in conducting the research project was the group interview or discussion group. These organised discussions presented some additional advantages ith regard to the individual interviews, because ideas and experiences are more likely to appear in group interaction. The discussion group was invited to visit the City Council premises, which was also a pretext for promoting this group's political and citizen participation, as well as a way to meet people with other intersex variations/DSD and discover common demands and differences. Again, the concealment and secrecy around these topics impeded participation. Similarly, it is still difficult to organise this kind of gathering or meeting outside of areas that are not strictly medical. In the end, five people participated in the discussion group.

Androgen Insensitivity Syndrome (AIS), Complete Androgen Insensitivity Syndrome (CAIS) and Partial Androgen Insensitivity Syndrome (PAIS)

Synonyms: androgen resistance syndrome, testicular feminisation syndrome, feminising testes syndrome, male pseudo-hermaphroditism, Goldberg-Maxwell Syndrome (CAIS), Morris's Syndrome (CAIS), Reifenstein Syndrome (PAIS), Gilbert-Dreyfus Syndrome (PAIS).

This syndrome is considered a genetic condition, inherited from the mother —except for spontaneous mutations in the egg— which occurs in approximately one in every 20,000 births. These people present the XY sex chromosome, however their bodies do not respond to androgens, also known as “male hormones” (an unfortunate term, given that all hormones are permanently active in both men and women) (Arana, 2005). In CAIS, the tissues are completely insensitive to androgens, and in PAIS the tissues are partially sensitive. Therefore, although the development of external genitals continues along female lines, the development of female internal organs has already been suppressed by another hormone —Mullerian Inhibitory Factor or MIF— produced by the foetal testes (via *grapsia.org*). Logically, there are no ovaries nor any possibility of menstruation.

Phenotypic features vary very widely, even within the same family. At the CAIS end of the spectrum, the outward appearance of genitals is typically female (according to the Quigley scale, AIS Grades 6/7) and the child is invariably raised as female. In PAIS, the outward genital appearance can lie anywhere being almost completely female (Grade 6), through mixed male/female, to completely male (Grade 1). When ambiguous genitals are present, they are typically described as an enlarged clitoris or a small phallus/hypospadias (via *grapsia.org*).

5-alpha-reductase deficiency

Testosterone is a biologically active hormone which is converted into another hormone in order to carry out its functions. This is possible through the existence of two enzymes, one of which is 5-alpha reductase. The inefficiency of this enzyme before birth and during puberty causes what is medically known as pseudo-hermaphroditism in men, or the atypical development of external genitalia or the urogenital tract. The classic form of this syndrome is characterised at birth by the presence of atypical external genitals (a clitoral-like phallus, hypospadias, bifid scrotum, urogenital tract consistent with a perineal vaginal orifice). Nevertheless, the outward appearance of genitalia can range from fully female to male with hypospadias and/or micropenis. The testes are usually found in the inguinal canal or scrotum. At puberty, unless a gonadectomy or removal of gonadal tissue has been performed, a significant virilisation is observed without gynecomastia or breast development, as a result of the effect of testosterone. The majority of sufferers are infertile (via orpha.net).

Congenital Adrenal Hyperplasia (CAH)

Synonyms: hydroxylase deficiency type I, adrenogenital syndrome, adrenal virilism.

This is thought to be the most common form of intersex/DSD among people with an XX karyotype, with an incidence of 1 in every 13,000 births (Arana, 2005) —it is estimated that the overall incidence of classic forms is approximately 1/15,000 and of non-classic forms of 1/1,000, although there are significant geographical variations (Labarta, Arriba i Ferrández, 2011). The most common cause of congenital adrenal hyperplasia is a deficiency of 21-hydroxylase . The term, congenital adrenal hyperplasia, encompasses a group of enzyme deficiencies (an enzyme is a protein molecule which is capable of catalysing a chemical reaction in the body) which are responsible for converting cholesterol to cortisol, which leads to a cortisol and aldosterone deficiency and to an excess of androgens which causes the virilisation of XX foetuses in the uterus. It presents a wide range of phenotypes, and the degree of virilisation is assessed using the Prader scale (1954) divided into five stages. Therefore, in medical terms for example, a girl with CAH-P1 has a mildly large clitoris (hypertrophy), with CAH-P3 she has atypical genitals (a clitoris which resembles a small penis) and with CAH-P5, she has typical male genitals. In all cases, menstruation is absent or irregular, but it can be regulated with treatments to reduce the androgen levels (Izquierdo and Avellana, 2003; Alba *et al.*, 2009; Donohone, Poth and Speiser, 2010; White, 2011). There is a potential for fertility.

Non-classic forms do not pose a medical emergency nor are they detected at birth, but classic forms are visible at birth and the salt-wasting form is a serious health condition which requires immediate medical intervention. These forms needs to be treated with adrenal steroids like hydrocortisone, prednisolone or dexamethasone (Conway, 2013).

Gonadal Dysgenesis

People with pure gonadal dysgenesis, 46,XX (Swyer syndrome) have gonads that are neither testes nor ovaries. They present rudimentary gonads or gonadal streaks which do not produce hormones and are extirpated because of the alleged high risk of malignancy. Outward genitals are typically female in appearance, with a normal vagina, fallopian tubes, hypoplastic uterus —which may be underdeveloped—, but with less development of secondary sexual characteristics.

Turner syndrome (45,X and 45,X mosaicism / 46,XX) is considered an anomaly of sex differentiation through abnormalities in the sex chromosomes (Audí Parera *et al.*, 2012) and is characterised by primary hypogonadism, short stature and, much less commonly, renal and heart malformations.

In cases of Swyer and Turner syndrome, puberty is brought about through the administration of oestrogens, and menstruation using a combination of oestrogen and progesterone (López Siguero, 1997; Capito, 2010). There is a potential for fertility through assisted reproduction techniques, embryo transfer and birth via caesarean.

Mayer-Rokitansky-Küster-Hauser Syndrome (MRKH)

In Mayer-Rokitansky-Küster-Hauser Syndrome or, in its abbreviated from, MRKH —which are the initials of the names of the four doctors who defined and classified it —the estimated incidence is 1 in every 4,000-5,000 women (Edmonds, 2000, 2001). It occurs during the foetal gestation period due to the lack of development of the Müllerian ducts, from which the female reproductive system develops: tubes, uterus, cervix and vagina. The vagina and uterus are either absent or very small. Despite that, the ovaries function normally, meaning that women experience normal female development during puberty, except for the absence of menstruation (primary amenorrhea). This is usually the first symptom, and the reason why it is often diagnosed during puberty.

Is not included in medical classifications as a form of intersex/DSD, however, the AIS support group includes this condition under its support umbrella. In this work, we have included the experiences of women with MRKH syndrome and those of their association, because, in our opinion, the psychosocial problems they face are very similar to those of other types of intersex/DSD —particularly in regards to androgen insensitivity.

Klinefelter syndrome and variants

This is considered an anomaly of sex differentiation through abnormalities in the sex chromosomes (Audí Parera *et al.*, 2012). It is relatively common — indications show an incidence of one man in every 500 (Conway, 2013) The karyotype 47,XXY is the most predominant, although other variations are included, such as XXXY or XXXX. Many classifications hesitate to incorporate it as a form of intersex (Audí Parera *et al.*, 2012), since the affected individuals "are of unambiguous sex and their anatomy does not present any intersex features" (German Ethics Council, 2012) ; but it does involve differences of sex development, which are often treated with hormones (as with Turner syndrome).

It is characterised by the presence of small, firm testicles, the absence of sperm during ejaculation and infertility. The genitals are not usually atypical, but gynecomastia is common from puberty onwards. The testicles produce a lower than average amount of testosterone, which means that individuals are not virilised in the same way as other men during puberty —growth of facial and body hair, deep voice, growth of penis and testicles. It appears that cases of men with Klinefelter are related to the uterus and ovaries (Arana, 2005) In any case, the main problems reported by associations of affected individuals include learning difficulties, developmental delays in speech and language, as well as a unique character profile. (Klinefelter's Syndrome Association UK, 2004).

Hypospadias

Hypospadias are defined medically as a congenital malformation when the opening of the urethra (or, the place where the urine exits the body) is on the underside of the penis rather than near the end of it in the distal position (*Diccionari Mèdic* [Medical Dictionary], 1990). It may be found from the middle of the penile shaft to the base of the penis, or even at the junction of the penis and scrotum. Dominique Salm defines it as the malpositioning of the urethral opening in men. (Personal communication, November 2009)

Cryptorchidism

This is a condition where one or both testicles has not fully descended through the inguinal canal to the scrotum.

Hypogonadism

This is a condition where the gonads (—the testes in males or the ovaries in females—) produce little or no hormones. Girls with hypogonadism will not menstruate, and it can affect their height and breast development. If hypogonadism occurs after puberty, symptoms are described as hot flashes, loss of body hair, decreased libido or the end of menstruation. In boys it is said that hypogonadism affects muscle development, the growth of facial hair and growing problems. In men symptoms are characterised by the growth of breasts, loss of body and facial hair, loss of muscle mass and sexual problems (via MedlinePlus).

AN ANALYSIS OF THE DIFFERENT REALITIES, POSITIONS AND REQUIREMENTS OF THE POPULATION WITH INTERSEX VARIATIONS/DSD (DIFFERENCES OF SEX DEVELOPMENT) IN THE CITY OF BARCELONA

Beyond the labels that are medically, socially and institutionally recognised (intersex, DSD —differences, disorders or anomalies of sex development—, etc.), the daily life of these people whose sexual characteristics (chromosomes, gonads, genitals, hormones, etc.) present different degrees of variation from the standard, regularly endure difficulties, obstacles and even violence at a social, family and/or health level. Therefore, the political intent is to eradicate the ignorance, taboo, stigma and discrimination that surround these people and their families, by implementing policies that meet their needs and demands. The Councillor's Office for Feminism and LGBTI of Barcelona City Council has embarked on the first phase of an investigation which aims to assess this reality in Barcelona.

To become familiar with the people involved; the individuals, groups (organisations or peer support groups for androgen insensitivity syndrome, Swyer syndrome, congenital adrenal hyperplasia, Turner syndrome, Klinefelter syndrome, MRKH syndrome, etc.) and the professional experts in the field in the city of Barcelona. We want to know which problems they come up against, their various stances, and above all what their proposals are for change. Once the mapping has been carried out, we will examine the role that Barcelona City Council's array of public policies can take on to promote, defend and guarantee the citizen rights of these individuals, based on the powers of the local government, and by coordinating the policies of different areas or sectors with respect to this group.

GENERAL (SOCIODEMOGRAPHICS):

- Age
- Sex
- Place of origin and place of residence
- Sexual-affective situation
- Cultural factors / religious beliefs
- Relationship with intersex (patient, parent)
- Diagnosis and degree of medicalisation / degree of chronicity and the treatment for this

PROBLEMS/NEEDS/ REQUIREMENTS

- Medical care
    - » Accessibility of medical services
    - » Communication between professionals and patients-family.
    - » Health needs / requirements
- Social / family
    - » Abuse / harassment
    - » Involvement in the family environment
    - » Sport
- Education
    - » Professional training
    - » School
    - » Society
- Employment
    - » Discrimination - demands
- Regulation/Legislation:
    - » Legal constraints (registration, administration, joining public bodies, marriage)
    - » Fundamental rights laws

PARTICIPATION IN GROUPS / POLITICAL COMMITMENT:

- Belonging to a rights defence organisation or support group for individuals with intersex/DSD.

- Which organisations for individuals with intersex/DSD are you aware of?

- Could we say that an intersex community or group exists?

- Do you think it is possible to create alliances between them when it comes to defining requirements and promoting legislative, medical and social change?

ASSOCIATIONS

- Main problems / obstacles / limitations (framework, volunteering...)

- Main requests

- Challenges

REQUESTS TO INSTITUTIONS

- In what ways could Barcelona City Council help / collaborate with your organisation or community

- Strategies

- Collaborations

- Incompatibilities

AN ANALYSIS OF THE DIFFERENT REALITIES, POSITIONS AND REQUIREMENTS OF THE INTERSEX/ DSD (DIFFERENCES OF SEX DEVELOPMENT) POPULATION IN THE CITY OF BARCELONA

1. Profession:...

2. Practising medical specialisation:...

3. Place of work:..

4. Years in this role:..

5. Medical coverage provided in your place of work:

a) Public

b) Private

c) Semi-private

6. Which intersex/DSD conditions/syndromes do you have experience in (include years of experience in each one):

....

....

....

....

....

7. Individuals/patients that are treated in your place of work:

a) Adults with intersex conditions/DSD.

b) Relatives

c) Others:

8. Areas of treatment or support provided to these individuals (give as much detail as possible for each case):

a) Gynaecology:..

b) Paediatrics:..

c) Endocrinology: ....

d) Paediatric endocrinology:..

e) Urology:...

f) Geneticist: ....

g) Psychology:..

h) Psychiatry: ....

i) Sexology: ....

j) Other:...

9. Is there a multidisciplinary team established in the medical centre where you work which is available to attend to births or cases of intersex/DSD (differences of sex development)?

a) Yes

b) No

c) DN / NA

10. Has an individual unit been formed in your medical centre where specific intersex/DSD cases are catered for?

a) Yes

b) No

c) DN / NA

11. Problems, needs and/or demands received from adults with intersex variations/ DSD (specify the syndrome if there are differences and the person's kinship or relationship to the condition). In the following areas:

a) Medical care: ....

b) Family: ....

c) Social:...

d) Education:..

e) Employment:...

f) Legislation/Legal:..

g) Others: ....

12. Problems, needs and/or demands received from parents and/or relatives of adults with intersex variations/DSD (specify the syndrome if there are differences and the person's kinship or relationship to the condition). In the following areas:

a) Medical care: ....

b) Family: ....

c) Social:...

d) Education:..

e) Employment:...

f) Regulation/Legislation: ....

g) Others: ....

13. What are the main problems/obstacles/limitations that you face as a care professional in these cases?

....

....

....

....

....

14. What do you think your priorities would be in terms of improving care or resolving these situations?

....

....

....

....

....

15. In what way do you think you can help or collaborate with Barcelona City Council to improve the care and quality of life for these individuals and their families?

a) Institutional resources:..

b) Strategies: ....

c) Collaborations:...

d) Others:..

BCN
An analysis of the different realities, positions
and requirements of the intersex / DSD population
(differences of sex development) in Barcelona

Ajuntament
de Barcelona