New managements in intersex debates

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The three authors of this communication[1] are working together on the socio-medical regulation of sexed bodies, basically through the pathologisation of sex/gender transitions and ambiguities, and the resistances generated at different levels. We would like to raise several questions in relation to that common interest and with our differences of analysis: (1) on the one hand, from the con/fusions of activism and academia, we wanted to give thought to the confluences, bridges and mutual learning processes between feminist analyses and practices and intersex activism; (2) on the other hand, we wanted to raise questions about new controversies surrounding the change of nomenclature from 妬ntersex conditions to 泥isorders of Sex Development 縫SD- (3); lastly, we wanted to situate those regulations and the resistance to them in our own context, at national level in Spain, with its cultural characteristics (social, political, health, etc.). This last point has made us realise the complexity of the different micro-resistances that emerge in the numerous negotiations between doctors and patients, in a context with hardly any political references of an intersex movement.

Dialogues, bridges and alliances between movements

We would like to highlight the myriad challenges that the intersex movement is posing to feminism and, in turn, acknowledge the conceptual and political resources that feminism has offered to intersex activism, all of which points to the need for policies of alliances between the two. Feminism and intersex activism share a common struggle in the field of sexual politics, but while feminism has focused on fighting oppression and male dominance, claiming women’s rights, as a political subject, intersex activism has been fighting against the numerous normative violences based on the naturalisation of sexual dualism and its ideal morphologies. Thus the analysis of social inequalities between men and women has been fuelled by a different, but necessarily related, analysis, on the “privileges of normalcy” (Engel, 1997; Hinkle, 2006), on oppression against people who do not fit in with the rules of sex/gender stereotypes. Based on a strong “woman” or “women” subject, or from the assumption of sexual difference as fundamental, feminism has been warned of the consequences of idealising certain gender

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[1] The paper we present here is part of a broader project called "Science and Technologies of the Body from a Science, Technology and Society Perspective" with two PhD project theses associated with it.

expressions based on duality which in turn give rise to new hierarchies and exclusions.

Thus then, intersex activism has “defied” and, in turn, joined forces with feminism, questioning the naturalness of sexual dualism (there are only two pre-existing sexes, male or female, and genitals are the determining sign of sexual assignation), and of the corresponding *natural* coherence between sex, gender and heterosexual desire. But it has also questioned the very distinction between “anatomic-sex” and “social-gender”.. Curiously enough, current medical treatments for “fixing” the sex of intersexed babies stem from the emergence in the 1950s of the “gender identity paradigm” which made a distinction between biological sex and psycho-social gender, criticising biological sex as a destiny (Haraway, 1991). This paradigm provided feminists with tools for their analyses on the social construction of differences and social inequalities. But the feminists did not question the physical component of sex and its duality, or the assumption of the existence of just *one*, invariable and irreversible “gender identity” (the success of which was assumed in medical protocols from an acceptable and functional external anatomy, adequate socialisation and heterosexual desire). In short, they did not question the role that the term “gender identity” was playing in medical control of sexual normality through the pathologisation of transitions, ambiguities and incoherencies in the sex/gender/desire system. Strangely enough, gender flexibility has been used to bolster the social rigidity of sexual dualism, through surveillance and control of the gender identity of persons diagnosed as having intersex syndromes and through surgical and hormonal treatments to adapt the bodies to the norms.

Through critical analyses of intersex activities, we understand that perhaps sex was always gender (Butler, 1990), and that materiality was already tinged with pre-conceived ideas about sexual differences (Fausto-Sterling, 2000). We learn about multiple sex, the semiotic-material multiplicity of the so-called only real sex, shown up when its different components do not match; the idea that there are not just two pre-existing sexes but a multiple combination of possibilities for chromosomic, hormonal, gonadal and morphological sex, etc. The choice of criteria for determining sex is a social decision. Intersex activism urges us to acknowledge this variability of sexual differences and to denounce acts of medical, legal and social gender violence that “correct” this variability, *making* bodies *normally* male or female in order to insist that people are men or women by *nature*.

Thus, the *fluidity* of sexed bodies made possible by technology is used to guarantee the *staticity* of gender duality in a social *black-boxing* process: if we can change biology through technology, why change the social aspect? The "biology is destiny" formula is reconceptualised by technology: Biology+Technology=Destiny. The increase in genetic discourses on the origins of intersexuality and eugenic proposals via prenatal diagnosis co-exist with the discourses on a technological progress capable to going beyond the limits of what is natural. With advances in medical technologies, hormonal biology and anatomy are more malleable to change than social gender-based norms and expectations. We find ourselves with *the malleable artificiality of natural sex and the sedimented naturalisation of cultural gender.*

Reconceptualising the category of "sex" and questioning its dualism is a profound challenge for society in general, and for feminism, too. Intersex activism has criticised the different treatment that the feminist movement has devoted to the critique of female genital cutting in Africa and to the critique of surgical interventions on intersexed babies: «"Their" genital cutting is barbaric ritual; "ours" is scientific. Theirs disfigures; ours normalizes the deviant.» (Chase, 1998:206). Intersex activists have also criticised the fact that some feminists do not consider them to be "real women" and as a result fail to consider their clitorectomies either (Chase, 2000; Hinkle, 2006). A feminist agenda that develops, as is the case in Spain, an "integral law on gender violence" should point out as well the micro-violences of gender, re-actualized daily and institutionalised, against persons who do not fit in with the social apparatus built on the naturalisation of sexual duality; point out how normative gender determines what qualifies as human and liveable (Butler, 2004); point out, for example, the connections between a law of gender violence and another law passed recently in Spain, the law on gender identity: the acts of violence that take place when the right to choose one's own sexed body and the very identity of gender are restricted (as well as the analysis of the social conditions of self-determination and of the meaning of autonomy).

The need to normalise bodies and put people in two categories implies gender and sexual orientation norms that affect everyone, but the surveillance, the vulnerability and the degree of awareness varies. If gender is taken for granted, at the same time it is under constant surveillance. Feminism has learnt much from trans- and intersex activism about *how woman is made*, about the daily construction of gender for all persons, about the different ways in which people “pass off” as men or women in social interaction (Kessler and McKenna, 2000). The analysis of how that “passing off” as a man or as a woman depends to a large extent on the attributions of others and on how different aspects of public physical appearance, speech, body control and the life stories themselves are dealt with, so as to be recognised as the “correct” gender. Feminism faces the intersex challenge of including in its policies and agendas the opening of spaces of possibility in order to make different sexed bodies and different genders, branded as erroneous, incomplete or unreal, liveable.

Female re/assignments[2] from a feminist point of view

Feminism has also put forward conceptual and political resources for denouncing sexist and androcentric biases in treatments of so-called “intersex conditions”. In the past, and until the new protocols on the medical management of babies born with a morphology that cannot be classified as typically feminine or typically masculine change things[3], around 90 per cent of these babies were reassigned and brought up as girls (Chase, 1998). These protocols and manuals on the treatment of intersex conditions put forward the idea that a male child with a very small penis or who cannot urinate standing up will never be able to enjoy healthy psychological development because of social rejection and mockeries. Feminists have criticised the *phallometrics* technique (Anne Fausto-Sterling, 2000) which determines which of these babies is male or not according to the size of the phallus at birth, which has to be over 2.5 cm, with the risk of it being amputated and of the baby being reassigned as a girl if it is smaller than that. However, as Cheryl Chase (2000: 124) points out, “what you produce is somebody who has a body that is vaguely female, is infertile, doesn’t menstruate, probably doesn’t have any sexual function, might have genital pain, and has been lied to and shamed. That is supposed to be less painful than having a small

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[2] We use the term "re/assignment" in order to call the moment when doctors provide with gender the intersexed newborn. This is the word used by part of the critic with medical managment on intersex, just thinking that the babies had their own sex or gender and doctors are externaly providing them another one.

[3] As a result of recent encounters between different groups of patients and relatives and the medical community, changes have been agreed in the protocols for early management of intersexuality that propose delaying surgical operations and which may, also, put an end to some sexist bias in reassignment. In this article, we refer to these recent encounters again when we deal briefly with the "controversy over the term DSD”.

dick? I think it is taken to be less painful because female pain is discounted. One it has been transformed into female pain it doesn't bother so much". The assumption is that if someone cannot perform the social role of "man" sufficiently well, or if technologies cannot get it, that person can always be made into a woman, by cutting off the surplus. The feminists have thus criticised the sexism of doctors in this respect, who however don't ask themselves whether a large clitoris prepares a girl for her feminine role or for a correct sexual function. On the contrary, they place emphasis on its ugly or attractive appearance. If a small penis "causes pity", the megaclitoris is perceived in aesthetically pejorative terms, it is "offensive", an "aberration", etc. (Kessler, 1998). The trap that masculinity sets itself, as an outcome of the androcentrism that exists in research and biomedical practice, reinforces a greater demand for adaptation to the masculine role. And the fact is that "everyone contributes in that way to making the impossible ideal of virility the start of an immense vulnerability" (Pierre Bourdieu, 1998). Thus, for example, compared to monitoring the size of the penis and the proliferation of standard measurements, the first tables on normative values of clitoris sizes did not see the light of day until 1980 (Kessler, 1998). The penis's greater degree of sociological significance entails far stricter surveillance and, on the contrary, the lesser degree of social significance of female parts has implied greater tolerance to variability. Paradoxically, sexism in research has led to less control of normative clitoris sizes, and probably a relaxation in the operations.

From a feminist outlook, there has also been criticism of the heteronormative and coitocentric notion of the genitality of men and women in terms of a perfect "fit" where, as of the historically denied or limited sexuality of women, the vagina appears to be defined only as a penis recipient, as if it only existed for the penis (Kessler, 1998), and not as an erogenous and pleasure-providing genito-sexual organ in itself. In general, the protocols are based on the idea that men have sex; women are penetrated and have children. The reproduction criterion is considered in a different way as well.

Sexism in these treatments and research studies reinforces the historical notion of women as *lacking*: for example, as lacking information in their chromosome endowment, because current biomedical science maintains that the only informant at the time of the development of an embryo is the chromosome Y; and accompanying these explanations with phrases such as "to form a male, something has to be added", "in the absence of Y, a female is developed"[4]; or as we mentioned earlier, as lacking sexual appetite and desire, accompanied by the lack of possibility of any pleasure other than that provided by the penetration of a penis. One of the arguments for massive reassignment to the female sex is that "you can dig a hole but you can't build a pole" (Hendricks, 1993:15). In this case, it would appear that subtraction provokes something more real than adding (Kessler, 1998).

All the foregoing is accompanied by the belief that medico-surgical techniques are developed more and better for creating typically female genitalia than for creating ones that are typically masculine. That is to say, it is considered possible to create a vagina capable of housing an adequately-sized penis but, admittedly, it is impossible for medical technology to create a penis with the erectile capacity to penetrate a vagina. The problem here again has to do with conceiving these vaginas simply as receptacles or holes, since the presence of a clitoris is often not even necessary (at least not until fairly recently and even then not clearly, since on many occasions the scalpel completely damages the sensorial capacity of this pleasure organ).

In short, for the time being at least and until the new management protocols can really start to produce new results, heteronormativeness and coitocentrism have really been the principal criteria on which to measure the success of the reassignments, far more than the very health or quality of life of these persons.

Controversies over the term DSD

Here we present an initial reflexive approach to what has happened in the last half year in the controversies over the term DSD (Disorders of Sex Development). In May 2006 an article was published, the outcome of a "consensus"[5] formed by medical professionals, patients and their relatives, which publicised the changes agreed for the management and medical treatment of babies hitherto called "intersexed" babies, as well as the change of name of the latter term to

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[4] Examples such as these can be found in almost all the current treatises on medicine used for training our future generations of doctors. Some more recent research is being undertaken on the functions performed by the X chromosome, a hitherto completely unexplored or relatively little explored area of research. (Javier Flores, 2001).

[5] I.A. I.A. Hughes, C. Houk, S.F. Ahmed, P.A. Lee, Lawson Wilkins Pediatric Endocrine Society (LWPES)/European Society for Paediatric Endocrinology (ESPE) Consensus Group, "Consensus statement on management of intersex disorders". *Archives of disease in childhood* 91, 554-563. See on: http://www.intersex-tr.org/documents/Consensus%20statement%20on%20management%20of%20intersex%20disorders.pdf

Disorders of Sex Development, shortened, preferably, as the acronym DSD. Since this article was published, there has been a controversy over the appropriateness or otherwise of the term, as well as harsh criticism by some groups of people who want to continue to call themselves intersexed persons, about the particular circumstances in which this proposal for nosological change has taken place[6]. And the fact is that many factors seem to come into play around this theme. In this paper we simply wish to present some of them and leave them open in the form of questions or approaches that provide food for thought, given the topicality of the matter and the complexity and wealth of the debates.

One of the key questions underlying the different debates on the change is the performative effect of medical categories. As regards the term itself, DSD, several issues are raised. On the one hand, the term seems to spring from the need to de-stigmatise and de-identify. In the former case, the need was stressed to abandon terms such as hermaphrodite or pseudo-hermaphrodite and for that purpose the term Disorders of Sexual Differentiation was proposed in the first place, as can be seen in an article written in 2005[7], but was later changed to the current term, Disorders of Sex Development. However when the definitive article was published, after the “consensus”, one of the key criticisms was of the term “disorders”, and there were proposals for it to be replaced by another term, such as “variations”, which was more acceptable (Diamond, 2006). The arguments for doing so were the same as those proposed for avoiding the change of nomenclature, and the fact is that, for many, the term “disorders” stigmatises once again, and maybe even more so, which is a step backwards in that it pathologises as well. Another circumstance that seems to be feared in the proposal for the term “Disorders of Sex Development” is that it promotes the inclusion of those “particularities” of development, now considered to be “incomplete”, in the glossary of congenital diseases, which might led to a highly different medical management of the matter than the present one, and perhaps give rise, in

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[6] For an example of this harsh criticism, see “The DSD Chronicles” by Curtis E. Hinkle from the Organisation Intersex International, on: http://intersexdocuments.googlegroups.com/web/DSD+Chronicles+OII-USA.pdf

[7] Alice Dreger, Cheryl Chase, Aron Sousa, Philip A. Gruppuso and Joel Frader, “Changing the Nomenclature/Taxonomy for Intersex: A Scientific and Clinical Rationale”. *Journal of Pediatric Endocrinology & Metabolism*, 18, 729-733 (2005)

some way, to prenatal regulations of a eugenic nature[8] (Hinkle, 2007).

This begs the question: by displacing terms such as hermaphroditism or intersexuality, does the term DSD de-stigmatise, or, on the contrary, does it fall into the pathologisation trap by proposing to use the word “disorders”? Could this de-stigmatisation be achieved by using another term such as the one proposed: “variations”?

As regards the need to de-identify the persons hitherto called intersexed persons, the new terminology, or the new acronym, prefers to use the name of something that the person “has” or “suffers from”, rather than something the person “is”, as the term intersexual was (or is) believed to do. That argument has been countered by some groups of people who question the consequences of doing away with that “identity-giving” (or community-making, if you wish) achievement of the word “intersex”, re-signified by the intersex activists themselves, and which has successfully mobilised a human rights movement and agenda. This movement has, in fact, been creating alliances for years with other movements, such as the feminist, transexual or queer movement, calling for policies of change in the strong sex/gender system and the acts of violence it creates. On the other hand, from one of the key US associations of intersexed persons, the ISNA, Cheryl Chase justifies “Why change the medical nomenclature?”[9] with the argument that 灯intersex” has been embraced by groups with a variety of social agendas not focused on improving medical care”[10]. From this perspective, the proposal is to sever the link of DSDs with gender issues, arguing that the term “intersex” implies a gender identity that frequently contradicts the gender identity of the patients, as well as being perceived as pejorative. It confuses a “medical condition with a label that implies an agenda of radical social change”. Nevertheless, in the view of other activists it is the medical condition itself that creates protocols based on constant surveillance of gender and of sexual orientation, more so than attention to associated health problems (Hinkle, 2007).

This begs the question as to whether, for example, including this issue on political agendas, such

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[8] See part of this controversy in the electronic letters published in response to the “Consensus statement...” article in *Archives of disease in childhood Online* http://adc.bmjjournals.com/cgi/eletters/91/7/554

[9] E-mail to the Organitation Intersex International (www.intersexualite.org) not published.

[10] In a previous article, key to the emergence of the intersex movement, Chase nevertheless was grateful about the climate of political criticism around the sex/gender system which she found when she moved to San Francisco and which enabled her to create what is the known Intersex Society of North America (www.isna.org).

as the feminist or the queer agenda, helps or hampers? Whether severing connection really helps de-identify, or whether its connection hampers rapprochement with the medical community and hence the change in the management protocols for these babies?

The whole controversy has mobilised relations, alliances and conflicts between the medical community, patients and relatives medical groups and the political intersex community. That prompts us to ask *how* medical “consensuses” are created, with what exclusions, and what role have new information technologies played in communications between the different actors, with different voices and perspectives, and in the dissemination of collective knowledge beyond medical or scientific contexts.

The "intersex experience" in the context of Spain

Once aspect that warrants a little more attention or which should, at least, be taken into account, is the sense and meaning of the theory and discourses developed around what has come to be known as intersex studies or critique, in particular situations, with particular people or groups of people and at particular moments in the past. The aim of this contextualisation is to avoid transporting models from other socio-cultural contexts to different social situations, because these discourses might cloud the analyses of the social situation that concerns us. The field work being carried out in Spain, and which embodies medical institutions and professionals who perform sex re/assignments, groups of people affected[11] by some 妬ntersex syndrome[12] , and people who have been diagnosed and treated, demonstrates the importance of taking the socio-cultural context into account when drawing up theory-based discourses and making them meaningful.

Just as the theory drawn up on the basis of “intersexual experience” has enabled us to de-essentialise bodies and identities, attention should now be paid to how and where we are using the very notion of intersexuality and the meaning that this theoretical discourse takes on among the persons involved. It would be advisable to be cautious and, in the process of deconstructing identifies, not involuntarily build a “strong intersex subject” which once again

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[11] We also find them as Mutual Aid groups or Self-help groups or “communities of suffering”.

[12] We have used the expression ‘intersex syndrome’ in this case because the associations are called by the label for

sidelined or undervalued identities that do not fit in with its subversive and political nature. Paradoxically, the political and intellectual intersex discourse is being sketched oblivious to the life of the large majority of people who have undergone a sexual re/assignment process at birth and/or at puberty in Spain, precisely when their existence has enabled this critique to be developed. We move in political and intellectual discourses that create models at times far removed from the individual experiences of the persons to whom they are directed appeal. Evidently, this intersex critique and theory arose from the experience of people who had undergone these processes, but it is also true that their life histories are characterised firstly by admitting that their bodies were used and abused and secondly by daring to denounce it, bringing to light their experiences. We could almost vouch for the fact that the *status quo* of the people who have gone through or are going through the same experiences in the Spanish context, and presumably that of many other persons elsewhere, is quite different.

Starting from a model formulated with such strength, both in terms of the dramatism of the testimonies it embodies and the very revealing nature of everything it implies, might make us run the risk of being dazzled and prevent us from seeing the little resistances which take shape from far less visible and more subtle positions. Failure to contextualise the theory that has arisen from intersex activism may make us fall into dual dichotomised thought. In a more or less explicit way, we find a theoretical discourse that, one the one side, situates the figure of the "oppressor", a discourse and a medical practice that does not discuss matters, that conceals information and sculpts and destroys bodies at whim in order to preserve socio-symbolic order. Its victims would stand on the other side, with no intermediate positions, anaesthetised by lack of information and by Propofol[13].. Another new dichotomy would be the one to do with building the intersexed person as an "object" or as a "subject", that is to say, occupying a position of victim or hero. The intersexed "object" would hide in the shadows, mutilated and dependent on medical power and its technologies; a victim awaiting a second or third surgery that reduces the effects of the first operation, unaware of the long-term effects of the hormones she/he is taking, and look, without success, for a medical professional who does not expose her/him to all her/his residents as a rare and exotic case which they may never come across again. On the other extreme, the intersex

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the diagnosis, which is usually the name of the syndrome.

[13] A drug used in operating theatres as a general anaesthetic in many surgical interventions .

activist “subject” would appear as the possessor of a great theoretical experience that refers to fluidity in bodies and in identities, who could even be found organising pickets at the doors of medical congresses on paediatric surgery or endocrinology.

Here in Spain we ask ourselves how to talk about intersexuality without intersexed people. We encounter the word “intersexual” or the expression “intersex condition” as such, in some of the papers presented at the most recent congresses on endocrinology or paediatric surgery, or in the title name of the “Intersex Conditions Unit” of Can Trias i Pujol Hospital in Badalona (Barcelona), but the fact is that the conditions become hazy behind the name. Behind the word there is no one, no group of people who identify themselves as intersexual and far less who elaborate theories reactionary to the established order of things. Does that fit in with the topic that Spain is ten years behind the United States, or perhaps with the traditional passiveness of the associative movement for which this country is criticised? One informant said: “All that stuff about intersexuality is a Yankee notion. I don’t identify with it at all”. Many other people have never heard of intersexuality, the intersex movement or activism, and on the contrary identify with some syndrome or disease although they do not know exactly what its nosological label is, while others, from support groups or groups of persons affected, identify themselves as CAIS or PAIS girls, as Turner women or Klinefelter men. All of them, from their heterogeneity, engage in constant negotiation and dialogue with medical professionals, parents, partners, friends, etc., to legitimate a life, bodies, a sexuality, that often contradicts the more normative systems of sex, gender and sexuality; lives in which we can identify countless what we might call “little resistances”, and when I say little, I am not referring to the fact that they have little value or importance, but to the fact of carrying them out day after day, in each act and daily experience. In these daily resistances, each situation or conversation turns into an area of creativity that brings about changes at micro level, but which, as a result of repeated and shared experiences, become areas of subversion and of knowledge that counteract the symbolic established order of things. Undergoing treatments and surgery is not exempt of agency and resistance. These people choose the strategic position in which to situate themselves, according to their interests at each time and place. Between holding up a banner that reads “Keep your scalpels away from us”[14]

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[14] A phrase reformulated from the original *Keep your scalpels off intersex kids!!* , from a photo taken in Boston in October 1996 at the picket organised by activists from Hermaphrodites with Attitude at the American Academy

and the suicide of Herculine Barbin, the well-known 19th century hermaphrodite, there are all sorts of positions.

The complex and particular relationship between Spanish care services, the medical professionals who work in them, the support groups of parents and adults and the persons diagnosed with some intersex condition[15] –whether or not they belong to an association- is full of contradictions and uncertainties.

Part of that uncertainty and contradiction has to do with the scant presence and/or healthcare system visibility –or the low prevalence[16], in terms of health statistics of these people and of these 苑athologies . As some medical professionals say, many people are not diagnosed or simply disappear after the diagnosis. This kind of intersex exoticism translates as a national medical panorama which, in the treatment of intersex conditions, is characterised by the non-existence of set protocols, of units of reference or of guided paths; the impossibility of monitoring and of creating patent databases; and by the difficulty of organising groups for conducting tests, clinical trials or genetic, epidemiological, clinical and therapeutic research.

All these medical difficulties denounced through patients’ associations call for new channels and strategies to be developed, thus enabling lay health knowledge to become the protagonists. What in the first place seem to be drawbacks, in practice imply a reduction in surveillance of these people, shaping a favourable framework for rolling out strategies that escape that control. There is where self-help and support groups reveal the contradiction, standing on a borderline with a tendency to opt for one territory or the other. One the one hand, they function as collective actors, where information is the most prized asset put into circulation in this network of reciprocities. They are areas or contexts that nurture the thought and criticism process, so that individual empowerment turns into collective response or vice versa. On the other hand, the use of clinical categories and the appropriation of medical-health insights signal a relationship with

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of Pediatrics, in what was considered to be the first political intersex action.

[15] When referring to the Spanish context, we use the term intersex conditions /intersexuality/intersexual in the same way as the term disorders or alterations of sexual development (DSD) when talking about medical discourses and practices, but never when referring to persons who have been diagnosed and treated under these condition labels.

[16] Proportion of new and old sufferers, per 1,000 inhabitants, of a particular disease.

the medical system that it also true. In any case, we find that strategic use is made of medical information, of healthcare services and of the resources and technologies they offer, highlighting secondary adaptations that combine technical guidelines and a complexity of practices vehiculed from the individual with her/his social network. Thus, for example, a certain proximity to biomedical guidelines and codes implies strategic alliances with the institutions and medical professionals from which and from whom more rapid and efficient access to certain tests or periodical controls that will avoid the side effects of interventions or medications is sought.

The current socio-health situation in the triad comprising healthcare services-self-help and support groups-persons diagnosed and treated is in fact changing, adapting and renewing itself constantly. In this area, the healthcare services appear as an unstable reality characterised among many other things by the dearth and ambiguity of the information they provide and by uncertainty as regards the effectiveness and side effects of treatments. The persons who are diagnosed and treated, whether from within or outside the framework of associations, stand in that area of tension and negotiations over bodies that choose to be built and controlled, that enter and come out of the system, and who, in that very act of entering and leaving, reproduce and contradict the sex-gender-sexuality formats. The answer to so much uncertainty and ambiguity is a continuous experimentation, which occasionally reduces, delays or avoids surgery or treatments. Often the decisions taken are underpinned by similar prior experience among relatives (aunts, grandmothers, etc.), and at other times may be the result of insight gained through information technologies such as the Internet. These explanations and reference points, which could be dubbed as “lay”, help make these people more self-sufficient, making their lives more meaningful and coherent.

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