

The Intersex Movement: Empowering Through New Technologies

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Abstract

The aim of this article is to explore the different demands and priorities of the intersex community as displayed in various Internet sites. It focuses on common and divergent viewpoints and strategies associated with the social, medical and legal regulations affecting intersex persons. It also demonstrates how online-based policy-making can lead to real actions and change, by allowing to provide information and support for intersex people, their families and supporters. This is oriented to reduce, if not eliminate, the shame and secrecy surrounding the topic, as well as inform and educate physicians and professionals specialized in intersex issues.

Keywords: intersex movement, rights, online communities, intersex organizations

1. Questions

The following three questions frame the study:

What are the objectives and demands of the intersex movement?

What are the main commonalities and divergences within the intersex movement?

What is the role of new information technologies for empowering the intersex community?

2. A conceptual background

The following conceptual framework is developed to emphasize some key notions that are central to this paper and will contribute to clarify the points to be debated.

When we talk about a social movement, the first idea that comes to mind is people with common interests or goals in a given space and time, bringing it close to the notion of community. Dorine Andrews (2002:64) defines community as “a set of relationships where people interact socially for mutual benefit”. The contemporary notion of community also refers to a kind of communication based on a new sense of belonging (Delanty 2003), which takes place in the context of continuously changing individualized groups. Thus, the stability and persistence of a community depends on its capacity to communicate new ways of belonging as an open-ended system of communication.

If we incorporate the notion of community in to a virtual context, we refer to a computer based online community, which would perform a similar set of interactions, but now computer mediated. Zizek (cited in Lovink, 1995) argues that “virtual communities” enable us to discover that we have always been virtual. According to this philosopher, the way in which we structure our encounters with other people is always an idealization and there for the form of constructing ‘reality’ and ‘virtuality’ is taken as a constitutive part of that reality. This shows us that there is a very narrow dividing line between the notion of a ‘real’ or non-digital community and the idea of virtual community. Additionally, the idea of community is closely connected with the notion of rights.

This is because the constraints of multipersonal interaction provide reasons for members of a society or community to claim or defend their individual and collective rights. The so-called adversarial conception of the linkages between community and rights, says that for rights to exist, there must be an inevitable existence of competition and conflict. Consequently, this theory emphasizes that those individuals who seek out rights, have an individualistic preoccupation to fulfil their own desires, regardless of other social goals. This perspective brings the idea that rights “atomize societies and alienate persons from one another” (Gewirth, 1996:2). The way we approach this connections, rejects the neoliberal idea that emphasizes only in the interests of the individual when referring to the colision between individual rights and community (Crawford, 1992). The intersex movement, human rights and other social or identity politics movements are based on a communal basis that cannot be translated into any substantial unity or only individual interests (Preves, 2002). As Frezzo states: [...] what is ‘thinkable’ as human rights depends not only on the accumulation of past struggles (e.g., movements of workers, women, people of colour, inhabitants of colonies, indigenous people, and innumerable other identity groups successfully pressuring governments and other authorities to make concessions), but also on the norms, customs, and practices that prevail in a given society in a specific historical period (Ishay 2008). Such conventions shape the perception of rights that have been achieved in other societies or in previous times (Frezza, 2011: 11).

In legal literature, it is common to read about three generations of human rights. In this classification, the first generation refers to the rights emerging from the American and French Revolutions to secure citizen’s liberty from any arbitrary action by the state. These rights are mainly civil and political. The second generation arose from the Russian Revolution and correspond to social, economic and cultural rights, also called welfare rights. Finally, the third generation of rights popularized by a former UNESCO’s Legal Adviser Karel Vasak, focuses on the key concept of global interdependence, which points out that states need to cooperate with each other to provide human rights. This classification was criticized for being minimally attractive and persuasive (Crawford, 1992: 39) and for not embracing the wide range of human rights abuses and ways to protect them. As human rights are not fixed social constructs, and to achieve an improved and critical approach towards them, there is a need for taking into account the relation of social, political and historical processes (Frezza, 2011).

The rights of intersex people have been continuously ignored through out history and as Hida Viloría argued (2012), the most tangible -though not the only- form of discrimination against intersex people has been medical. Such discrimination includes non-informed surgical genital interventions, hormonal treatments of gender re-assignment, the denial of clinical information, intentional loss of medical records by clinicians and hospitals and also the denial of the very existence of intersex people. This, all together with the denial of their freedom as citizens, is certainly, a human rights issue. Intersex activists work and fight for their claims collectively. Even though activism might refer to individual acts of defiance (Baumgardner and Richards, 2000: 283), it encompasses collective actions that involve a sense of solidarity, a sense of shared identity and common will, and the desire in pursuit of transgression (Jordan, 2000). In this respect, Jennie Kermodé, chair of Trans Media Watch,¹ notes how the ideas about activism can differ widely:

I find the concept of 'activism' quite problematic. It means different things to different people and it is often stigmatised, associated with complaining or with interfering in areas one knows little about. I'm interested in working collaboratively with other individuals and organizations to achieve results that are good for society as a whole. I think it's a shame that society increasingly presents passivity as a virtue. I believe that being well educated (which requires ongoing effort), having a good grasp of current affairs and dedicating at least part of one's spare time to trying to improve society is an obligation for every citizen. Most of us enjoy great benefits from our civilization and from democracy, even if we don't often pause to appreciate them - it is our duty to do what we can to maintain them and to provide for the well-being of future generations as those in the past provided for us.²

¹ Trans Media Watch is an organization which goals are “to combat prejudiced, sensationalist and inaccurate depictions of transgendered people in the media. It is run by volunteers and depends on ordinary people within the trans community to be its eyes and ears. It aims to reflect the concerns of those people and of the community as a whole”. Information available in: <http://www.transmediawatch.org/about.html>. Retrieved on the 17th of June 2012.

² Kermodé, Jennie. E-mail interview (June 10, 2012).

As the notion of activism can be approached from different standpoints, in the specific sphere of human rights activism is oriented to overcome inequities and to achieve certain goals. In the same way in which we have introduced the notion of community into the virtual space, we can think of 'online' activism both as a complement to an 'off-line' activity, and also as an only internet-based type of activism. In the former case, the purpose is to enhance or empower an actual form of off-line activism, and in the latter, the online platforms are used for purposes that can only be possible using the Internet (Vegh in McCaughey & Ayers, 2003). Additionally, online activism can be categorized in three main areas: 1) awareness and advocacy, achieved by letting people have access to the information about the cause and by creating a network of information distribution; 2) organization/mobilization, which entitles offline and online actions that tend to influence the readers to participate actively for the cause; and 3) action/reaction, which mainly refers to cyberattacks or hackactivism, but could be seen as well as the very different ways in which users, participants and readers react to the content of the online platform (Ibid.,71-75). For the purpose of this study, we understand online activism³ as a politically motivated movement that uses the Internet as its main medium of communication (Vegh en McCaughey & Ayers, 2003).

The cross-linking of the concepts mentioned above can be constructed and analyzed as a dispositive. According to Jaeger (in Wodak & Meyer, 2009: 39-41), Foucault conceived the notion of dispositive to 'permit a better analysis of history and current reality in which the question about the relation of discourse and dispositive is of vital importance. As illustrated in figure 1 bellow, the idea of dispositive represents the network that can be established between a heterogeneous set of elements (discourse, institutions, rules, moral and philosophical thoughts) and other extra-discursive practices that involve actions (Foucault, 1991: 28).

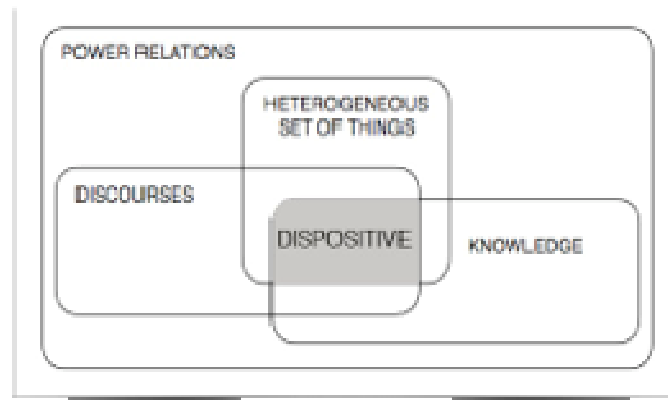


Figure 1: Dispositive

The concept of dispositive has a strong relation with the notion of power; that is to say, a dispositive is used as a tool for analyzing or understanding different forces within a dynamic social field. Therefore, the analysis of a dispositive can allow to understand critically and at grass-root level power/knowledge relations. In every social movement, there is an occurrence and overlap of different force relations such as objects, means, discursive and extra-discursive manifestations that are constantly in movement, tension and contest. This can be understood as a network of power/knowledge relations in a complex system of subjection and resistance, which Foucault calls dispositive (Ibid.). For this reason, a community, organizations with equal or different aims, sets of ideas, bodies of norms, and even strategies of resistance, constituted as an heterogeneous group of elements that comprises a social movement, can all be approached and analyzed as a dispositive. Accordingly, a social movement takes shape as people become convinced to get involved in collective actions on sustained basis. Its participants can contribute in private and public forms and may be linked through direct or indirect ties, involving themselves in specific activities within the community (Diani & McAdam, 2003). A dispositive, then, will shape the behaviour and interactions of individuals and individuals will shape the dispositive in turn. Following this, we can say that a dispositive is embedded in social life (Delanty, 2003: 169).

³ Different approaches to the notion of activism can be found in Ganesh & Zolle (2012); Harlow & Harp (2012); Rotman, Vieweg et al. (2011).

The generative and innovative dynamics of social movements lead to re-arrange the habitus⁴ of thought and behaviour in a society, creating new spaces and ideas, and putting unquestioned assumptions and practices into question (Crossley, 2002: 36-37). As human behaviour, collective identities are constantly changing and evolving. For this reason, relationships within a social movement among people, organizations and groups, constitute alliances through differential and sometimes oppositional structures that shape the definition of their boundaries (Diani & McAdam, 2003) and contribute to the affirmation of collective identities. Even though it diverges into various important aspects of other human sexuality politics movements such as gay, lesbian, trans and queer activism, the intersex movement incorporates numerous common points for which strategic alliances are promoted and recommended. However, there is a claim that in a social movement, alliances are not possible in all cases and contexts, and this depends mostly on how inclusive and balanced are the benefits for all parts involved and its mechanisms of participation.

In view of the above, the notion of a social movement implies the existence of a community. The complexity and plurality of identity choices that constitute any community suggests that the set of discourses and practices that occur within its boundaries will never be homogeneous. Even if certain social goals and demands are relatively integrated within a community, they shall not be exempt from differences and contradictions. In this regard, and in relation with the establishment of strategic alliances, Kermod (2011) argues that:

Most people who threaten or discriminate against transgender and intersex people couldn't tell you the difference between them, and don't care. Much prejudice against LGB people is rooted in dislike of their perceived transgression of gender boundaries. At Trans Media Watch we believe the focus should be on the aggressor, not the victim. If a cisgender person is the victim of transphobia, we'll still stand up for them. We don't believe this diminishes public awareness that minority groups are subject to the worst discrimination overall, even if the public has only a limited understanding of how those groups might be defined.

[...] Alliance-building is the only way anything ever gets done in politics, in the long term. Women in the UK wouldn't have got the vote without male allies. Black people in the US wouldn't have ended slavery without white allies. It is important that such movements are led by those whom they primarily affect, for example, transgender people should not be speaking for intersex people - but the more people who follow, the better.⁵

Therefore, engaging in meaningful dialogue with intersex people and their family members, and also with the people who have the power to influence decision and policy making is central to start creating opportunities (Greenberg 2012) and to achieve the community goals. The debates regarding the establishment of alliances depict different standpoints and they involve different issues including the implications of alliances with the medical community and also with identity politics movements (Greenberg 2012).

3. Intersex activism

Since its inception, the intersex movement has essentially been a human rights movement⁶ (Sytsma, 2006: 73-86), being one of its principal goals to stop the shame and secrecy surrounding the birth of an intersex infant. It started in the United States during the nineties, by organizing protests at medical gatherings, and also by developing a support network for the intersex children and their families (Herald, 2010). This movement was born as a way of confronting and protesting against medical procedures given to babies whose genitals did not correspond with the binomial, hegemonic and socio-historical construction of two standard sexes: male and female. The first public demonstration by intersex people took place in 1996 outside the annual meeting of the American Academy of Paediatricians, and its purpose was to claim that such medical procedures violate the human rights of the child and subordinate the value of sexual pleasure to notions of heterosexual normality (Kitzinger, 2004: 453).

⁴ By *habitus*, Bourdieu (1990) understands the generative set of schemas from which subjects perceive the world and act on it. These generative schemes are socially structured, they have been formed throughout the history of each subject and involve the internalization of the social structure, of the particular field of social relations in which the social agent has been formed as such. At the same time, according to this author, the schemas are structural, since they are the structures from where thoughts, perceptions and actions of the agent are produced.

⁵ Kermod, Jennie. E-mail interview (June 10, 2012).

⁶ To review the Intersex Society of North America's version of the history of the intersex movement see "What's the history behind the intersex rights movement?" available in: <http://www.isna.org/faq/history> . Retrieved on the 7th of November 2011.

These claims were focused mainly on the serious and sometimes irreversible consequences of cosmetic genital surgeries, especially when they were performed even if they did not represent a health problem or a serious risk for the life of the infants,⁷ and also when there was not any real benefit contemplated for them. Curtis Hinkle, the founder of the International Intersex Organization,⁸ expressed concerns about the usual medical premise that 'nobody's gender can be left in limbo'⁹ to justify the cosmetic surgeries to intersex babies. According to Hinkle, The person is the one who has to decide about its own gender, not the doctors or parents. Sincerely I can't understand why they think in this way. In their imaginary, they believe that if we are not gendered since we are born, we can be at risk. Let the people decide by themselves! Remember that many medical statements are based in old traditions, a kind of imaginery that has little to do with reality.

A child won't be in gender limbo. A child will tell you which sex they are. Stigmatizing to the child is telling what sex the child is. When I was a child I couldn't see beyond the boundaries. But when I started to grow I did. The child will tell you what they want to wear, which toys they want. They will tell you.¹⁰

As stated above, medical decisions can affect the life of the infants in irreversible ways. Patients must be able to have a say in the medical procedures that can affect their children's lives, and when there is no life risk or health damage, any decision regarding sex assignment should be delayed until the child is old enough to decide.

Clinical management of the intersex child is also frequently based on the assumption that the only way to alleviate the parent's anxiety facing the born of an intersex baby is to fix his/her genitals surgically, in order to assign a sex early and rapidly (Holmes, 2000). Thereby, Iain Morland (2007) considers that clinicians justify surgical interventions to intersex babies for the supposition that they will be bullied in the 'locker room'. In this respect, Morland argues that the locker room is turned into a 'looker room' in which the relationship between looking (at the genitals) and knowing (what gender the person is) must be secured by surgery. On her part, Kermode (2012) thinks that the primary cause of children being teased and bullied is because of a lack of confidence:

Kids can always find something to bully over, be it freckles, glasses, being "too fat" or "too thin", having an unfashionable jacket, having sticky-out ears, liking the "wrong" television programmes or being intelligent. The way to stop a kid being bullied is to ensure that, right from the start, they feel loved and supported and good about themselves. We don't do that by telling them they're mutants and that bits of their bodies need to be cut off.

I've worked on a number of cases where children have decided to be open about being transgender or intersex in their primary schools. I've found that children are overwhelmingly accepting. When one is a child, the world is full of new and surprising things. Something like this very soon comes to be seen as ordinary. When there is prejudice it comes from parents (sometimes the parents of other children) or teachers. No child should have to undergo life-altering surgery in order to make adults happy. Adults should take responsibility for themselves.¹¹

In recent years, there have been considerable advances regarding intersex management, not only to the prospect of clinical management, but also to a multidisciplinary approach, which considers the fundamental rights of the person. Thanks to the work of intersex advocacy organizations, activists and people who work on intersex issues - intersex and non-intersex-, and also to a greater accessibility to new technologies, especially Internet and social media, there is a bigger amount of information available, and doctors are increasingly considering patient's fundamental rights.

⁷ There is vast evidence documented, that these surgeries can cause physical and emotional harm. See Beh & Diamond (2008); Diamond & Sigmundson (1997); Gregori Flor (2006); Holmes (2008); Kessler (1990); Morland (2008, 2009); (Preves, 2002: 532).

⁸ OII is a coalition of different intersex activists and organizations from around the world with many different views and voices. Even though some of the organizations selected for this study are affiliated to OII, the opinion of each board member of the organization represents their own opinion. This gives the study a more diverse background, since the statements and demands of the different organizations -even if they follow common issues- vary according to their location, cultural and geographical context.

⁹ See Melton, Lisa (2010).

¹⁰ Hinkle, Curtis. Videoconference interview (November 15, 2011).

¹¹ Kermode, Jennie. e-mail interview (June 10, 2012).

4. The role of new technologies

New information technologies need to be more democratized to enable social networks and the media to fulfill their roles as strategic tools for raising public awareness, to inform and educate people. Zoltana, a freelance writer, journalist, artist, photographer and performance poet who runs the blog Zollies-Spot,¹² asserts that thanks to the Internet, she could unveil a hidden ‘secret’ about her identity which changed her life:

I didn’t find out about my intersex condition until I was about 34-years old. It was 1995 and the advent of the “world-wide-web” came to my fingertips when I bought my first home computer and got internet access. It was such a miracle for me! It empowered me to think for myself and ask myself questions in a challenging way; and, therefore, to see what I could find out about this “syndrome” my sister and I learned we had and to see if this miracle of internet could provide clues to a secret that my parents and doctors refused to talk to us about. I remember typing the term “Feminizing Testicular Syndrome” in the search engine and -- lo and behold -- an avalanche of information was there for me to read. That night, at 2:00 a.m., I learned more than I ever expected to learn from credible websites and medical sites. The first thing I felt, after reading and re-reading online documents for hours, was relief. I had finally uncovered and removed this huge burden of ignorance about MYSELF! How empowering is that? To be able to learn a secret, a mystery, that for some reason I was never made privy to regarding ME.

Numerous people from the intersex community are increasingly using new technologies to get information, to organize, debate and also to provide information, share experiences, resources, and to give advocacy¹³. Even if on-line activism does not guarantee ‘off-line’ success, Internet has become a very powerful tool to coordinate efforts and to promote actions in everyday’s lives, and as Zoltana argues, it can be used personally as a medium to overcome and stop shame and secrecy:

For me, being creative and expressing myself is my outlet to tell the world, “Hey, I’m here, I’m not going anywhere. THIS IS WHO I AM.” Dealing with my intersexuality through my creative expression is very therapeutical for me. It is my way of discarding the shame that was imposed upon me for so long and it shackled me into feeling like a hollow nothing. Sometimes I write poetry about the intersex experience and may use a photograph that I took. It is very cathartic for me. Once I express myself artistically and either blog about it or show it to someone it is my way of announcing that I am here and I am speaking out and NOBODY will ever make me feel ashamed about who I am. With that said, I also hope it helps others like me, as so often is the case, there are many intersex individuals who feel so alone or are feeling the way I felt for such a long time: the feelings of shame and loneliness and a sad acceptance that you will always feel that way.

Intersex activists and individuals in general, can take advantage of Internet in order to disseminate experiences, knowledge, meanings and claims and also, to be more influential in re-shaping society and institutions by defying and changing hegemonic notions of sex and gender. (Still, 2011) Hiker Chiu, intersex activist and founder of the International Intersex Organization China, considers that there is an urgent need to help promote intersex issues not only in media, but also in society as a whole, sharing resources, giving awareness and educating people:

In China, most of the people use western medication, and here, doctors do perform cosmetic surgical interventions to intersex infants. One of the problems is that many people do not have access to information in order to prevent this to happen. Information and publications help to spread the word and to let people know that intersex issues are about all of us, not only intersex people. It is important to share intersex life stories, and to let people know that not only gender is diverse but also sex. In the last years, the web-site of OII China has considerably increased the number of visitors and I guess facebook has helped a lot, becoming as well an important tool to have more real effects in the life of people.¹⁴

¹² [Online] Available: <http://zollies-spot.blogspot.com.es> (July 12, 2012).

¹³ This is not to minimize the fact that just as many intersex people do not have access to new information technologies or even the provision of basic education in some parts of the world.

¹⁴ Chiu, Hiker. Videoconference interview (November 8, 2011).

According to Kermode, the use and access to new information technologies also presents some risks: [New information technologies] can be useful in disseminating suppressed information, but they are not the answer in themselves. The key issue is distribution. Trusted brands, such as traditional newspapers, will inevitably influence more people than lone voices, regardless of who is speaking most truthfully (or, indeed, most eloquently).

The biggest issue facing minority groups in relation to new media is that we are entering an age where we will no longer be able to stem or control the flow of information. Consequently, we need to move away from protective frameworks structured around censorship and start tackling underlying problems in human interaction. We have a very short time period in which to work. For instance, by changing the way traditional media talk about transgender people now, we can shape majority attitudes before public conversation moves entirely into the social media sphere. We cannot eliminate problem attitudes but we can position them as belonging to social outliers, significantly diminishing their power and ensuring that, over time, society at large will come to view us more sympathetically.¹⁵

As pointed out above, in spite of the democratization of access to new technologies and the increased information available, many medical protocols on intersex management around the world are still perpetuating and putting into practice obsolete concepts and procedures that keep affecting seriously the life of intersex people¹⁶. New information technologies are a useful toolset to get information, to organize, achieve goals and disseminate information. However, there is also a need to work ‘out of the screens’ in order to eliminate definitely these harmful practices and to bring about social change.

5. Priorities and demands

The most common medical ‘treatments’ of intersex bodies are the removal of the gonads, genital surgery and hormone replacement. As a result, many intersex people are infertile, insensitive to sexual stimulus, and unable to produce vital hormones, resulting in serious secondary conditions, in addition to psychological harm and severe pain caused by these medical procedures (Veith, 2011).

Even though cosmetic surgical interventions are a central issue within the intersex movement, there is also an urgent need to give attention to other important and central aspects, not erasing any other problems and working on a wider range of experiences. Thus, as Hinkle declares, focussing solely on infants, childhood and medicine, infantilizes and medicalizes intersex, and “If we don’t care also of what happens to intersex adults that were surgically intervened with when they were infants or if we don’t discuss the serious constraints of the binary system of sex and gender, we are not doing a good job”.¹⁷

The very diverse demands of the intersex community have varied over time and it was not until September 2011, during the world’s First International Intersex Organizing Forum -which took place in Brussels- that different priorities were agreed by activists, experts in gender and human rights and members of advocacy organizations from all around the globe.

Among the topics discussed, the consortium explored various perspectives from which to approach intersex issues -gender queer, human rights, medical, juridical, among other standpoints-; the needs and priorities of the community; ways to advance in equality for intersex people; possible and needed alliances and working methods to advance in the identified priorities. The agreed priorities resulted in:

1. To put an end to mutilating and normalizing practices such as genital surgeries, psychological and other medical treatments, including infanticide and selective abortion (on the grounds of intersex) in some parts of the world.
2. To ensure that the personal, free, prior, and fully informed consent of the intersex individual is a compulsory requirement in all medical practices and protocols.

¹⁵ Kermode, Jennie. E-mail interview (June 10, 2012).

¹⁶ Some medical protocols still follow Dr. Moneys’ advocacy of sex and/or gender binary reinforcement, promoting surgery upon the genitals of intersex newborns. However, there is an increasingly disapproval of his theories which resulted from the very negative consequences of the sex and/or gender assignment to infants by medical and psychological practices. See Colapinto (2000).

¹⁷ Hinkle, Curtis. Videoconference interview (November 15, 2011).

3. Creating and facilitating supportive, safe and celebratory environments for intersex people, their families and surroundings (ILGA, 2011).

These priorities had become the most important goals to achieve for the intersex movement. The experts, who constitute the Forum, will continue building wider alliances with other human rights and equality organizations, including new working areas such as women, indigenous and the rights of people with disabilities.¹⁸

The priorities agreed in the Forum are highly connected with the claim of autonomy, which can be translated into the right to decide for one's own body¹⁹ and gender identity. This idea of autonomy does not imply a total independence of institutions and/or society, since they must recognize them when performing a claim inquiry. Thus, and as stated by Judith Butler (2011), the right of self-determination, more than being an individualistic option, is a way of recognizing the other as part of oneself, repositioning the idea of autonomy within an ethic of care:

It seems to me, when members of the intersex community demand autonomy; they do it toward the medical establishment, medical and legal institutions, to religious institutions.

One must address all the social and political institutions in order to have certain level of autonomy. We are dependent on these institutions that help and also hurt. Autonomy is not individualism because the intersex community act as a group.

The institutions should support me, and thereby I acknowledge my dependence. Questioning and reformulating what good care is, is another thing. I do not think we have to cling to the idea of volition or autonomy but relocate it outside the ontology of individualism and masculine ontology that leads to confrontation.²⁰ There for, the notion of autonomy implies at the same time the recognition of certain levels of dependency. As infants and children cannot assert their autonomy, they must not be subjected to unnecessary and harmful surgeries, which they may not have chosen as adults. Intersex infants and children have the right as any other person to be raised without cosmetic surgery and/or hormonal treatment when they are not related to health problems or life risks.²¹

As a result, the claim for rights implies a need of support from others. In this regard, Kermode affirms that: The intersex community is simply articulating itself as the disabled community has done in the past. We are all members of society and we are all, initially, dependent on others. Not one of us gets through life without any state support, even if, in some countries, that support exists only in the form of things like the creation of roads to travel along or the provision of childhood vaccinations. Yes, some of us need more support than others, but then, some of us contribute more than others, and not just through formally recognized means. Because both these things are impossible to measure, we accept that the balance won't be the same for everybody and it becomes reasonable to say that we should all deserve a certain level of support simply for being human. Our obligation, in return, is the same as that which rests on everybody else: simply that we contribute what we can; that we do our best.²²

Nowadays, cosmetic genital surgeries performed on infants and post-operation treatments are considered a human rights issue.²³ In order to cite some specific actions taken to protect intersex babies from these procedures, in 1999 the Constitutional Court of Colombia established protection of the human rights of intersex people, by restricting the authority of parents and physicians to authorize medically unnecessary genital plastic surgery. In 2005 the San Francisco Human Rights Commission and in 2009 the Australian Human Rights Commission declared that the intersex management protocols for intersex babies lead paediatric specialists to violate their patient's human rights.

¹⁸ The second forum on intersex organizing will take place in Stockholm from 9-11 December 2012.

¹⁹ See Yogyakarta Principles (2007).

²⁰ Butler, Judith. Personal communication. Workshop "Body, memory and representation: dialogue between Judith Butler y Adriana Cavarero". Autonomous University of Barcelona (July 11-13, 2011).

²¹ See "Intersex Children" [Online] Available: <http://www.genitalautonomy.org>. (July 30, 2012).

²² Kermode, Jennie. E-mail interview (June 10, 2012).

²³ Gender expression and sexual orientation are seen and recognized as a human right, by the United Nations. See United Nations (2011) and also Yogyakarta Principles (2007).

Argentina approved on May 2012, a groundbreaking gender identity law, becoming the first country in the world which not only enables people to change their names and sex on their official documents without the need for approval from a judge or doctor, but also guarantees the protection of the right of gender identity of the children. With this, any surgical intervention or hormones treatment must be previously approved by an expressed consent of the child, taking into account the principles of progressive capacity and interest of the child, and the Argentine law 26.061 which regards to the comprehensive protection of the rights of children and adolescents.

6. Intersex on-line advocacy platforms

The way we have approached the questions of this work is by exploring through simple direct observation on-line narratives of Internet sites that give information regarding intersex issues and/or provide support and advocacy for the intersex community.

As Paula Heinonen (2011:7) rightly states, ‘narratives tell us much about culture and the nature of culture, but narratives have no meaning without reference to their sources’. For this reason, and to complement the analysis and strengthen the findings of the study, the results were triangulated with focused interviews, personal communications and testimonies. In this way, far from analyzing the group of Internet sites selected as a one-way source of information, they were explored as a dispositive. Accordingly, we not only dealt with the content of the web sites, but also with a network of meanings and relations through which people communicate and interact, paying especial attention to the voices of the people involved. This methodology offered us a more simple and reliable generalization for identifying knowledge and information that may not be obvious to a casual user/observer (Barab, Kling, Gray, & ed., 2004) and to provide us a broader understanding of the intersex movement and its implications. The sites selected include advocacy sites, on-line information platforms and personal blogs, thus providing a more diverse and global dimension to the analysis.

The online platforms/technologies used by most of the intersex organizations and groups are web sites, blogs and social networks. For the purpose of this analysis, we have chosen 10 diverse Internet sites. They serve as a source of information for professionals, parents and general public; to give support to intersex people, families and allies; to get involved in ‘off-line’ activities; or simply function as a personal blogs with information and personal testimonies and opinions regarding intersex issues. Not all of them are dedicated exclusively to intersex issues but to a broader range of people, communities and topics. Some of them are not being updated and are maintained only as an important source of information available to all.

Serving as a reference, the following table lists the selected sites, the type of on-line platform analyzed, its geolocation, and the corresponding URL (Uniform Resource Locator):

ORGANIZATION GROUP	PLATF ORM	COUNTRY/REG ION	URL
Accord Aliance USA	web site	USA	www.accordaliance.org
Anrogen Isensitivity Syndrome Support Group (AISSG)	web site	USA	www.aissg.org/
EKTA Foundation	web site	India	http://ektafoundation.blogspot.com/
Intersex Awareness	web site	New Zealand	www.ianz.org.nz
Trans Media Watch	web site	Scotland/GB	www.transmediawatch.org/
Zollie-spot	personal blog	USA	http://zollies-spot.blogspot.com.es/
Intersex International Organization	web site	worldwide consortium	www.intersexualite.org
Intersex Society of North America	web site	USA	www.isna.org
Intersex Society of South Africa	web site	South Africa	www.intersexualite.org
The UK Intersex Association	Web Page	United Kingdom	www.ukia.co.uk/

Table 1: selected OAP.

7. Findings

As stated in the methodology, the exploration of each Internet site through direct observation of its content, the interviews, testimonies and personal communication with activists, bloggers and intersex advocates, provided us with a better understanding of the diverse priorities, statements and demands of the intersex communities, which we summarize below:

- There are common and differing approaches regarding intersex issues within the intersex community.
- In the World Wide Web there is a diversity of intersex online groups, aimed to give support and/or information to intersex people, families and allies.
- There is a wide variety of Internet sites -personal and organizational- dedicated to or addressing intersex issues, such as specific on-line sites only for intersex people who have received medical treatment; those which are focused in a specific variety of intersex; those for intersex people, advocates and allies in general; sites dedicated to providing information for parents and clinicians; personal blogs with comments, statements and/or testimonies of intersex people; others dedicated to provide information to users in general and sites that are not actually updated but maintained online as a source of information.
- Many sites address the need to educate parents and doctors regarding intersex issues, and state that sex and gender are not determined by unique biological characteristics of male and females.
- There is a strong controversy regarding the terminology when referring to intersex issues. Some declare that the medical consensus on the term “Disorders of Sexual Development” (DSD) allows a more integrated and patient-centered care, while others state that far from being a terminology problem, it pathologizes sex/gender variances and dismisses the informed consent of the child.²⁴
- Psychological counselling from other intersex individuals in childhood and early adulthood is seen as potentially producing a positive outcome for the lives of intersex people.
- There is a need to change the medical protocols on intersex management and medicalization.
- In keeping with the demands of the first Forum on Intersex Organizing, there is a general agreement to stop cosmetic genital surgical interventions on intersex babies, to protect the right of decisional autonomy and bodily integrity, and to claim for the right of informed consent and self-determination.
- There is a need for juridical protection regarding intersex issues, especially those that refer to informed consent, self-determination and the right for embodying the perceived sex and gender identity.
- There is a need to provide referrals for medical and psychological support for intersex persons -children and adults- and their families, and to encourage retrospective studies on genital cosmetic surgery in order to evaluate the possible long-term consequences.
- Intersex activists and academics need to work more on the constraints of the binomial system of sex and gender.
- Neo-eugenics is a new concern for the intersex activism and there is a need to work on questioning its premises.
- There is a need to spread the word and take action in real life, not only in cyberspace, talking to intersex people, doctors, academics, students, organizations among others.
- Alliances with other communities are recommended, respecting and truly taking into account the needs, interests and priorities of each community.
- It is recommended to work with NGO's, education institutions and media to promote best practices.
- Internet is an important tool for activism but it does not guarantee offline action by itself.
- The on-line activism/advocacy can lead to diverse off-line advocacy and educational opportunities.
- Autonomy or self-determination regarding body and gender identity must be guaranteed by law, protecting the fundamental rights of children and adults.

Even though, the findings don't represent the total and continuously changing universe of the Internet sites dedicated to or advocating intersex issues, and the wide range of the demands and priorities of the intersex movement, it shows different perspectives and priorities that are being discussed or rised.

²⁴ Moreover, terminologies like true hermaphrodite, female or male pseudo hermaphrodite, sex reversal, intersex and medical names of various specific conditions, have their detractors and supporters (Klein, 2011).

As stated above, the analysis of the dispositive, including the Internet sites, the interviews and personal communications, revealed key concerns regarding medical issues such as cosmetic genital normalizing surgeries, screening and neo-eugenics, medical treatment, health care for infants, children and adults. All of them connected with ethical and human rights themes, such as decisional autonomy, the central interest of the child, informed consent, social gender roles, gender diversity, gender assignment, gender expression and sexual rights.

Additionally, other important points considered are the need of international, regional and local regulation of intersex management and medicalization by law, the importance of educating doctors, parents and society at large on intersex issues, the need for safe, supportive and celebratory spaces for intersex people and the acceptance and celebration of sexual diversity. None of these elements must erase other problems since all are important, not only for the intersex community but for society in general.

Furthermore, there is a strong need for society and professionals to understand and accept sex and gender diversity. Educating and acting for sex and gender diversity is as well a crucial aspect for the success of the intersex communities objectives and claims, but also a key element to reduce shame, secrecy and inequalities.

Internet has become a very important tool for social movements, playing a fundamental role in the mobilisation of people through solidarity demonstrations, awareness campaigns, social protests for political, economical, legal and medical reforms among others. For the case of the intersex movement, Internet has helped to disseminate information and demands around the world, contributing to coordinate local, regional and global actions. New information technologies are a key resource to generate action, by means of on-line campaigns that in order to have a positive effect must be translated into real life or 'off-line' actions. The central role of the Internet in today's social movements is changing not only the way they are structured but also the way and extent in which social and political actions are being carried out. However, Internet does not mobilise people and institutions by itself, and the success of online activism, depends on deeply committed advocates, their credibility and 'real life' work.

As Curtis Hinkle (2011) states, the best way to support on-line advocacy is "to interact with people in real life, to make a lot of phone work, to visit doctors, institutions, NGO's, again, to make information available to people, to establish new contacts, to help people to relate with each other, and to be supportive".

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