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Emelie J. Ali Ms
Manhattanville College

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FACEBOOK AS A SOCIAL OUTREACH AND ADVOCACY TOOL
IN INTERSEX/DSD GROUPS

Emelie Ali
Manhattanville College
December 6, 2017

FACEBOOK AS A SOCIAL OUTREACH AND ADVOCACY TOOL IN INTERSEX/DSD GROUPS

1

This research aims to analyze how U.S. advocacy groups have adapted to the internet as a resource to gain supporters and provide knowledge. There is much psychological research on small groups of intersex people worldwide, but few studies venture into advocacy based research. Intersex organizations and support groups will have produced agendas to address intersex conflicts, especially through means of conscious raising. Conscious raising is a method, drawn from feminist literature, that bring awareness to a topic that is considered radically different from the norm (Dictionary). Dialogue in itself can be seen as an advocacy tool to raise awareness. This research explores how social media can be a support system and advocacy tool simultaneously, through a netnography of Friends and Families of Intersex People (FFIP), an online Facebook group. Throughout the study, two major themes have appeared: gender & sexuality and resisting the use of gender assignment surgery on infants and children. The U.S.'s mainstream notions of gender & sexuality have shaped the medical community and its reaction to intersex conditions on a large basis. This in turn has affected the general population's understanding of biology and gender.

Among the biological spectrum, some humans have been born as neither male nor female. These people have been described as intersex, and other such terms. Intersex, or Difference of Sex Development (DSD), is described by the Intersex Society of North America (ISNA) as a general term used to describe multiple conditions in which a person is born with a reproductive or sexual anatomy that differs from typical definitions of female or male (Intersex Society of North America). ISNA continues to explain that Intersex conditions vary from ambiguous genitalia to having mosaic genetics so that some chromosomes are XX and others XY (Intersex Society of North America). Intersex or DSD should not be understood as only an external physical condition. Some intersex peoples are born with the physical appearance of one

FACEBOOK AS A SOCIAL OUTREACH AND ADVOCACY TOOL IN INTERSEX/DSD GROUPS

2

sex, whilst having the internal structure of another. There has been few research studies conducted on the experiences of intersex individuals. As a result, there has been much ambiguity and misconceptions about intersex conditions and what the proper protocols should be regarding their place within society.

Physicians have attempted to alleviate this ambiguity by subjecting intersex people to fit within the confines of the sex binary. Concealment method care has become the norm among medical practitioners: physicians have conducted genital surgeries on infants, in some cases without the consent of the parents, or by instructing parents to keep their child's status confidential while rearing the child to a gender that matches the new genital appearance. Such practices stigmatize intersex bodies as abnormal.

Some intersex people have then become activists to change the concealment procedures to one of patient oriented care. Anecdotal accounts of intersex people's experience with the medical community and the general struggles against societal norms have been shared with the public. Intersex support groups and advocacy organizations have since been founded (since the 1990s) to spread awareness and build community. As technology has progressed, the internet has been used as a tool for activism. Social media websites have become profoundly popular and have made it easier to share information with large amounts of people at a time. Thus, some online communities have developed and used the internet as a means to increase their own ability to engage in discussions and awareness.

SOCIETAL DISTINCTIONS OF BIOLOGICAL SEX AND GENDER

Society relies on habitual behaviors to maintain its institutions. Institutions such as the family and government determine how people understand and interact with one another. In order to rationalize events and to determine the basis for behaviors and laws, societies must first create social constructions. Gender and biology are two such constructions that lay out the foundation for appropriate attitudes, aspirations, and ability to access resources. Gender was not used as a human category until the 20th century in order to distinguish and outline notions of masculinity and femininity (Rubin 2012:886). The governmental institution then built regulations restricting some people based on these concepts of masculinity and femininity, such as an attempt to restrict primarily affluent women to the home. Aspects of biology then intersected with concepts of gender, as an endeavor to naturalize established norms, thus the bio-political materialized into gender (Rubin 2012:886). Biology and gender became parallel, creating a binary in which primarily outside sexual characteristics defined a person's gender identity. Human variation was limited to male and female, ignoring the many aspects that create a biological spectrum, such as chromosomes and gonads. This restrictive view of biology has been particularly destructive to intersex people, the realities of their conditions, and their identities.

The Conceptualization of Gender

The understanding of sex relations in the United States relies on the country's conceptualization of gender and sex. Identity is dependent on location, culture, and time. Western individualistic countries have used gender and sex as a means of self and external categorization, where identity is constructed in relation to and in contrast to other people. (Schmader and Block 2015:475). Previous researchers, Wood and Eagly, have categorized the understanding of gender as either traits associated with masculinity and femininity, or as a self-

FACEBOOK AS A SOCIAL OUTREACH AND ADVOCACY TOOL IN INTERSEX/DSD GROUPS

4

categorization within male and female social groups (Schmader and Block 2015:474).

Masculinity and femininity are relatively vague terms that encompass expected assigned roles, behaviors, and appearances that exist on a spectrum. The term “tomboy” for instance is used to describe a young woman or adolescent that engages in what are considered masculine traits, such as wrestling or wearing non-effeminate clothing (Dictionary). The masculine traits are not perceived as erasing or transforming the woman identity. Gender conceptualized as within male and female social groups however, insinuate a common notion that gender is determined by specific sexual characteristics, which then dictate social development.

Cisgenderism ideology correlates with the practice of assigning gender based on biology and further delves into societal responses. Cisgenderism explains the assumption that external, authoritative gender designation is superior to self-designation (Blumer, Gavriel, and Watson, 2013:269). This ideology also reinforces the gender binary and purposefully ignores other societal practices that are less gender rigid. A cisgenderist perspective calls for a universal notion of gender that is irrelevant to relational status, and insists a person can only sustain one gender identity throughout their lifespan. Most importantly, this ideology strives to label those outside the binary as inferior (Blumer et al. 2013:269). Studies have argued that gender is a spectrum that is highly influenced by the sociopolitical environment, rather than perceived notions of natural biological dispositions (Anderson 2016:177). This is not to say that biology has no effect on gender identity. Biological characteristics have been ascribed social meaning, so that body parts are seen as recognizable distinctions within gender categories. As a result, certain physical traits are internalized, much like masculine and feminine traits (Schmader and Block 2015:478). Biology alone however does not explain nor develop the entirety of a person’s gender identity. An essentialist biological narrative, gives a false dichotomy that gender roles are universal; in

reality, there are differences between child rearing methods across families, which in turn can result in different perceptions of gender within the same culture and society (Berenbaum 2006:10). For instance, parents may assign gender to a child based solely on the child's behavior (Berenbaum 2006:5). Since gender assignment is heavily subjective, there needs to be flexibility in addressing the possible causes to self-identified gender. It is necessary to deconstruct gender in order to understand the prejudices towards those who do not ascribe either to a gender or biological sex binary. Misconceptions about gender have resulted into malpractices within the medical community

The Conceptualization of Intersex

The construction of gender in societies has led to debate about the legal function that gender holds. Due to stigmatization of those outside the binary, gender non-conformists have used a rights based approach in addressing gender based discrimination (Rubin 2015:55). Increasingly, since the 1990s Intersex advocacy is following this approach by showing the lack of legal protections for intersex people: those who do not fit the standard categories of male nor female (Rubin 2015:55). It should be understood that biological variation is common. The ISNA website lists the statistical data that demonstrates how many people are born with certain intersex conditions. It is estimated that one in one hundred births are categorized as neither fully male nor female (Intersex Society of North America). Thus, limited knowledge of human biology allows for misconceptions, which in turn effect how society responds. A holistic approach to human variation is essential, for providing information that is relevant to the real conditions of our species. When and how genital surgery is performed is predominately dependent upon the physician's opinions about how to proceed (Berenbaum 2006:15). There is not a systematic approach to intersex bodies, due to a lack of research analyzing the outcomes of genital

procedures (Berenbaum 2006:15). The intersex community's very existence is a threat to the pre-established norms that still hold weight in the twenty first century. Sharon Anderson, a nurse instructor, claims that assigning gender based on blood chromosomes or genital appearance is bound to have potential error (2015:176). Anderson further concludes that biology is not destiny (Anderson 2015:176). Human anatomy is not a form of predestination that establishes personality and identity. People need to accept the variation that truly exists in terms of biology and gender, so that human complexities can be further analyzed.

Influence of Gender and Biological Concepts on the Medical Community

These current notions of gender and biology are shaping medical practices and how society deems who has control over their bodies. Policies regarding intersex individuals still follow a structure created by physician John Money (Anderson 2015:177). Money insisted that gender was malleable until approximately the age of two, thus genital surgery was a solution to any psychological trauma that may ensue from not automatically fitting into the binary (Anderson 2015:177). Parents were then instructed to raise the child according to the gender assigned by the physician that correlated to the new genital appearance. This very practice is a contradiction in itself. If gender is a natural process determined by anatomy, then there is not a reason to rear a child according to any segregated gender standards; the child's gender would be determined by their environment without any imposed will. Money was given the chance to put his theory into practice when a child's penis was accidentally removed during a circumcision (Berenbaum 2006:10). The case was referred to as John/Joan, and the child was reared as a girl after a feminization surgery had taken place. Physicians concluded that the best method would be to transform the male genitalia structure to resemble a vagina. The child was later revealed as David Reimer, who did participate in what were deemed feminine activities, such as wearing

FACEBOOK AS A SOCIAL OUTREACH AND ADVOCACY TOOL IN INTERSEX/DSD GROUPS

7

dresses, but later Reimer came to reject the woman identity and reclaimed a man identity later in life (Berenbaum 2006:5). Reimer was originally considered a success due to his participation in effeminate actions, but his gender identity as an adult proved Money's theory to be a failure. Although there is doubt about the validity of the John/Joan case, as there are assumptions that Reimer was raised as a boy for the first seven months, it still displays the reality that gender may change over the course of a lifetime. Reimer's case also questions which aspects of a human determine who gets placed under the male or female category. Reimer did not have a penis, but the rest of his body was unaltered; thus, the appearance of sexual characteristics were enough for Money to consider the sex assignment surgery a success. Reimer's internal structure and other biological characteristics were ignored in favor of genital reassignment. While there is yet to be an exhaustive study conducted on intersex persons and their perspectives on the procedures, there is anecdotal records of collective dissatisfaction with the medical community.

These medical practices have often excluded the voices of the intersex peoples themselves. As activists began to surface in the 90s, debates ensued over the proper medical and psychological procedure for intersex individuals (Preves 2003:1). The activists advocated to destigmatize intersex conditions, arguing that genital surgery were initiated to alleviate the fears and concerns of physicians and parents, thus not preventing trauma for the child, but rather for the psychological fears of those non-intersex (Preves 2003:2). The major ethical problem for intersex people, is that the conditions themselves are not life-threatening to the child, only threatening to their culture (Rubin 2012:884). Parental cooperation is deemed essential by activists and physicians to ensure the child a healthy psychological development, hence activists argue for more comprehensive and inclusive patient based care (Preves 2003:3).

ETHICAL CONCERNS IN INTERSEX MEDICAL PROCEDURES

Correlation of Sex Assignment and Gender Identity

One major research study, titled “Ambiguous Genitalia with Perineoscrotal Hyposadias...,” was predominately referred to by physicians to reinforce and justify their choices for surgical procedures (Melby 2002:5). The research entailed 39 participants over the age of 21 who specifically were treated at the John Hopkins Hospital. The participants were grouped based on their specific intersex condition for anonymity (Migeon et al. 2002:2) The survey questions included whether participants were satisfied to dissatisfied about their physical appearance, genital function for intercourse, and their gender identity based on the physician’s assignment (Migeon et al. 2002:2-4).

Results revealed multiple surgeries and medical procedures were necessary for all participants. Two participants had undergone sex assignment surgery twice (from female to male to female) (Migeon et al. 2002:5). A majority of the participants claimed to be satisfied with their physical appearance and gender rearing: 76% of men and 78% of women satisfied, with one particular case in which a woman was dissatisfied, due to the difficulty of being homosexual (Migeon et al. 2002:6). When asked about sexual orientation, men claimed to be exclusively heterosexual, whereas women were not exclusively heterosexual. Researchers suggest the men’s responses might be affected by homophobic social pressure, making them feel obligated to pick that choice (Migeon et al. 2002:8).

Questions on intercourse focused on whether men were capable of getting erected and if women were able to have intercourse. While it was concluded that majority of participants regardless of gender had intercourse, there was dissatisfaction with their genital functions, including the inability for women to lubricate, which caused discomfort (Migeon et al. 2002:6).

The purpose of the study was to compare success rates of sex assignment matching gender identity. It is not clear throughout the study what the researchers conceptualized success to entail. There were high rates of dissatisfaction for sexual pleasure and lack of emotional support. The study also seemed to equate the participant's ability to engage in sexual activity as successful genital function, which ignores the emotional and pleasurable aspects of intercourse. The research questions did not delve into personal satisfaction with the treatment itself, as it was common to constantly partake in surgery and use medication over the course of a lifetime. It remains unclear how the participants feel about coping with their conditions. The researchers concluded that there should be more transparency between physicians and parents so that parents understand the long-term effects of genital functions post-surgery, possibility of continuous hormone therapy, and the possibility of reproduction (fertility is not always considered when determining sex assignment by physicians). The general wellbeing, physical and mental, appears to be ignored for the sake of cosmetic appearance and gender rearing.

Intersex Psychological Experiences

A more recent study approaches the psychological effects of intersex conditions and the treatment the participants received. The "Gender Identity and Coping..." study also consisted of seven feminized 46,XY individuals who filled questionnaires about their experiences with medical treatment, puberty as an adolescent, distress, and gender identity. Gender identity was a scale asking if they felt most like a man, woman, or both (labeled as transgender) and whether they felt a third gender category should be incorporated (Schweizer et al. 2009:194). Research questions were aimed to discover how treatment affected self-perceptions (Schweizer et al. 2009:192).

All patients described confronting heightened insecurity, isolation, and even contemplation of suicide (Schweizer et al. 2009:194). All participants mentioned feelings of distress during puberty, as they were constantly under hormonal medication and had frequent visits to physicians, resulting in feelings of shame for not having a “normal” body, leading to a notion of “otherness” (Schweizer et al. 2009:194). This notion of otherness was developed around the ages of four or five.

The participants expressed being hopeful that further surgery, such as vaginoplasty, would alleviate anxiety about gender identity. Some participants questioned if surgery would make them “more of a woman,” and thus worth the constant medicalization and physical discomfort from vaginal dilation (Schweizer et al. 2009:195). There was dissatisfaction with gynecological care, as gynecologists treated the intersex bodies as a standard female body, thus not providing adequate care (Schweizer et al. 2009:195).

Despite feminization surgery and being reared as women, gender identity varied among the patients. A participant by the name of Fiona, wanted a sex change to a male body, but was dissuaded by her mother, who feared the family would face disapproval from their neighbors (Schweizer et al. 2009:196).

When questioned about society offering a third gender option, the participants divided into two groups (one declined to answer the question). Three participants claimed a third gender would give people flexibility, as there was more time to decide if one wants to identify as man or woman. The other three suggested a third gender would not alleviate the complexity of intersex identity, but rather reinforce the notion of assigned gender. A participant named Claudia argued that the gender binary should be eliminated altogether, with an aim to make human gender variations socially acceptable, as a designated third gender for intersex people would

unintentionally invalidate intersex people's self-designated gender identity (Schweizer et al. 2009:197).

The study revealed that psychological distress was not only present post-surgical transition, but also after a gender was assigned. Only one participant claimed to have emotional support that she could share her intersex conditions with. This parallels responses demonstrating that silence and shame about participants' intersex experiences were common. Participants addressed dealing with distress about their condition at adolescence throughout adulthood, indicating coping was an ongoing process. Surgery was demonstrated as having an impact on the participants' self-worth (Schweizer et al. 2009:198). Although the sampling frame was not large enough to be representative of intersex experiences, the study did prove that intersex conditions influenced how the participants conceptualized their own gender, how it affected their self-worth, and dissatisfaction with medical treatment and lack of social acceptance. The Likert scale used to determine the participants' gender identity, however, described transgender as simultaneously having a man and woman identity. This gender description misrepresents the transgender identity, and closely correlates to the modern term gender fluid, which entails not having only one gender. The researchers' explanation of the term may have altered the participants' comprehension of transgender and changed the survey results.

Gender and biology, although two separate entities, continuously intersect. Both studies revealed a correlation between people's body and their identity. The participants in "Gender Identity" research constantly referred to non-intersex bodies as normal, and hoping that surgery would lead to a more normal body. This demonstrates how social perceptions of bodies has described any body type outside from the approved male/female standard is then abnormal, something that needs to be fixed. It appears from the "Ambiguous Genitalia" study that intersex

surgeries are performed to parallel with the gender binary, hence why child rearing by parents is another important factor (Rubin 2012:891). Gender is constructed at multiple institutions, Fiona mentioned wanting to change to a male identity, but was dissuaded by her mother. Parent's comprehension of gender is essential for child rearing and can become a force of distress for the child.

Criticisms

ISNA claims intersex peoples' trauma originates from the stigma associated with their conditions, not from gender norms (Rubin 2012:885). The organization does not put much pressure on the effect of gender norms, so that intersex gender identities are not invalidated. However, based on the results of the aforementioned studies, gender identity and norms have a direct effect on medical practices and stigmatization. Society's fetishism of a gender binary, urges physicians, parents, and individuals to conform to that norm. Hence, intersex activists and some physicians pursue patient based care as opposed to concealment centered care (Melby 2002:4). ISNA has criticized the "Ambiguous Genitalia" research for focusing on matching gender to sex assignment, noting that it did not include questions revolving around their participant's mental health nor their experiences with treatment (Melby 2002:5). Researcher David Rubin that reducing the problems intersex people face to types of medical care, similarly reduces intersex people to consumers (Rubin 2012:901). Intersex communities face many obstacles, including the quality of therapy, where they can access that therapy, medical treatment, and family and social acceptance. ISNA disregard for gender in its activism ignores the sexism and inequalities that surround gender, such as the need for gender to begin with (Rubin 2012:904). Other activists have suggested implementing de jure laws to protect people from de facto prejudices (Douthirt 2012:11). Implementing such laws whilst the general society

remains ignorant to gender and biological variations, will not provide the most aid. There needs to be comprehensive educational access to the general public to widely challenge prejudices and give intersex people the tools they need to stay healthy physically and psychologically.

INFLUENCE OF MEDIA ON INTERSEX CONDITIONS

Media's Political Influences

The research "Modeling the Effects..." conducted online surveys at a large university to assess online political expression to external efficacy (Zhou and Pinkleton 2012:824). There were a total of 434 participants, whose age averaged around twenty two years old (Zhou and Pinkleton 2012:819). A questionnaire would have statements, such as "I like to stay informed about elections," followed by a Likert scale for a response. The overall data revealed that media of all types, from opinion blogs to direct news sources, were helpful resources for the participants to be informed about political events (Zhou and Pinkleton 2012:819). It was also common for participants to use different news media simultaneously (Zhou and Pinkleton 2012:825). Media provides accessibility to information, which combined with civic interest, can result in greater public participation in local political activities (Zhou and Pinkleton 2012:825). The type of media participants' consumed paralleled with their interests and became a means to exchange information among others (Zhou and Pinkleton 2012:826).

The results demonstrated that media is used as a personal political tool and means for sharing information. The research questions did not evaluate if the participants' decision to become politically involved was directly influenced from the media. Although the research is not exhaustive, it does produce an understanding as how media is used among young adults. This study is vital for showing alternate ways for activist groups and politicians to expose their platforms. Intersex organizations could incorporate media as a way to spread knowledge and

awareness. It requires a plethora of campaigns to inform people about the conditions, and create a network of support for advocacy that can be shared to attract allies. Advocacy organizations may have to determine what the general interests are of their main supporters and develop a plan to attract those who remain neutral to their form of activism.

Intersex in the Media

Discovering the most effective way to distribute large amounts of information is particularly useful when counteracting misinformation. “Reading between the Lines” archival research studied 108 popular newspapers between the years 1993 to 2013. The data was based on how many articles were written about intersex conditions. Intersex conditions were reported based on the medical treatment offered as a response to the conditions.

The year 2004 and each exceeding year contained a political frame surrounding the intersex topics. This frame tended to focus on the supposed risks associated with intersex conditions (Bergner 2014:10). Unlike articles based around advocacy, political frames did not have an individualistic perspective. It created comparisons of intersex to other diseases, such as being deaf, and claimed that intersex people who rejected their physician’s treatment were similar to the deaf who resisted learning to speak (Bergner 2014:13). It mentioned the possibility of unknown risks resulting from lack of treatment, such as the possibility that not providing synthetic hormones to those with congenital Adrenal Hyperplasia (CAH), could increase chances of homosexuality (Bergner 2014:18).

Overall the majority of articles pushed medication as a solution to intersex conditions, with the intention that these conditions be seen as defects (Bergner 2014: 22). The articles reinforced stigmas about intersex bodies being diseased (Bergner 2014:26). Activists then have a

challenge due to such an overwhelming amount of information made to delegitimize patient based care, and justify intersex being labeled as a bodily emergency.

Media and online information in the 20th century is predominately used to establish a platform for sociopolitical agendas. The “Reading between...” archival research demonstrated pre-established notions of where intersex people belong in the general society. With such a plethora of antagonistic information about intersex conditions, activists will have to find ways to educate a large amount of people. Micro conversations tend to reach a wide audience (Douthirt 2012:695). Previous articles relating intersex people as abnormal rely on macro and meso perspectives. Thus, activists can use anecdotal records to gain sympathy. Activists can also mention the ableist parallel journalists used to compare the deaf to the intersex. The deaf learning to speak may not personally be convenient, rather it is convenient for others without that condition to not have to learn sign language, as a result placing the burden on the deaf person. Similarly, “correcting” intersex conditions does not always alleviate pain for the intersex person, but rather allows the physician and parents to avoid adapting past the habitual binary.

As sociopolitical climates continue to change, activists should seize the opportunity to use the internet as an advocacy tool. “Modeling the effects” revealed the influence of political resources. If most of the online data about intersex conditions are negative, then activists will have to challenge common binary ideology. Activists should then collect data about the political interest of their supporters to find a potential platform to help share their goals. News media can encourage people to participate in civic engagement. Stressing on the importance of patient care, deconstructing the binaries, and releasing personal accounts of intersex people can all be included within a website. Media is a persuasive tool to enable political action.

LITERATURE REVIEW ANALYSIS

Embracing human variation gives individuals the ability to harbor a sense of personal empowerment. Support and self-help groups aim to increase assertiveness and knowledge about rights to increase that feeling of empowerment (Marija and Rozman 2015:362). Since the problems intersex people face is multifaceted, organizations must ensure to integrate the multiple challenges. Advocacy comes in many forms. Intersex activists may not have the luxury of presenting advocacy in a way in which they are able to address “both sides” of an issue; rather their approach must be direct, where they confront the specific problems (Fox 1986:70). Intersex solidarity can be built at community levels, but with access to online sources, intersex solidarity can expand, becoming transnational. Transnationalism provides collective identity and reinforces that variation is neither simply a biological nor personal experience, but global (Vicair 2014:107). Intersex advocacy is not solely a matter of human rights. In order to fully understand the world and accept the differences among the seven billion people in the world, societies must move past their ethnocentrism, and embrace the spectrums within reality.

WESTERN CONCEPTUALIZATION OF INTERSEX CONDITIONS

The History of Stigmatizing Intersex/DSD conditions

How societies have come to treat and understand Intersex/DSD people stems from a long history of negative interactions. The early onset of stigmatization towards Intersex/DSD conditions perhaps stemmed from the same branch of able-bodied ideology. Any “abnormal” child born during the 16th century was understood as a condemnation from God, due to the sinful behaviors of the parents, or more specifically, the mother (Reis 2009:3-4). There was an assumption about which bodies were considered the norm. Even in the 21st century, there is a general sense of pity or disapproving attitudes towards differently abled bodies in the United States. It is then understandable that beginning notions of intersex conditions were met apprehensively. People who had genitalia that were neither distinctly penises nor vaginas were originally categorized as hermaphrodites. When people were categorized as hermaphrodites in the 1800s, their conditions were described as hybrids, monstrosities, and other such dehumanizing names (Reis 2009:24). Despite the frequent use of the word “hermaphrodite,” medical practitioners were not yet convinced a human could have both fully developed genitals (a penis and a vagina simultaneously) as the name suggested, thus “hermaphrodite” was a vaguely defined term (Reis 2009:8). As more medical records were made about hermaphrodite conditions, arguments for what constituted as hermaphroditism increased and were highly debated. Such a case included an instance where a person had more developed breasts and a menstrual cycle, yet did not have a defined vagina; this then led to a debate over whether this “man” should truly be considered a man simply because of the genitals, when there were other more predominant sexual characteristics (Reis 2009:35).

Interestingly enough, it was not the non-normative genital itself that seemed to pose a problem, but rather the notion that a person could deceive society by being able to change their gender (Reis 2009:30). Society has, and continues to, use human categories to determine customs and laws. A potential gender fluid person was a threat to the gender legal system in place in the U.S. and U.K.

In the 17th and 18th centuries, hermaphrodites were largely considered women with enlarged clitorises (Reis 2009:18). The major concern then was that these types of women were capable of penetrating other women, could mask themselves as men and vote or keep property, and in other cases, would be unable to consummate marriages (Reis 2009:35). The concept of a woman being able to do any of the aforementioned activities was a threat to the status quo. This hints at the performative nature of gender. If one was capable of “passing” as that of another gender, then gender itself is able to be manipulated. Thus, the general fear of potential hermaphrodites was more of a social anxiety about women and potential homosexuality. This mentality influenced surgical practices performed predominately to fit people into a sex binary.

Surgeries originally were meant to fix the social problem of marriage. “In deciding the sex of their patients, doctors sought happy endings, hoping to see their patients embrace at least one element of womanhood or manhood: marriage. Physicians first attempted interventionist surgery on genitalia in the hope of making those organs serve the doctors’ perception of patients’ sexual and marital requirements” (Reis 2009:45). The surgery would be deemed a success if the patient performed activities associated with the enforced gender identity (Reis 2009:47). Of course what constituted as appropriate gender roles in the 18th century would not parallel with the 21st century, yet this ideology continues into present day. The sex binary is so intricately linked with a gender binary, that despite notions that people can participate in whichever

activities they enjoy, there is still a sense of what is appropriate. This concept of “appropriate” has concrete consequences, and in terms of enforcing “normality,” these consequences can be life changing. Gender and intersex/DSD conditions were linked together from the beginning of medical and cultural understanding.

Development of the Term “Intersex” and “DSD”

Hermaphrodite has brought confusion and debate among physicians. Contemporary terms still carry some confusion and debate as the current vernacular continues to progress. Hermaphrodite is deemed an inappropriate categorization since it was conflated with negative terminology and inadequate bodily functions (impossible for humans to have two fully functioning reproductive systems). The term Intersex was then utilized in the 90’s, but as of 2005 the phrase Disorders of Sex Development was used by Lawson Wilkins Pediatric Endocrine Society and then by the European Society for Pediatric Endocrinology (Reis 2009:153). The use of the term DSD (Disorders of Sex Development abbreviated) was favored due to its focus on genetics, thus presenting atypical conditions as a medical situation rather than as an identity (Reis 2009:154). The push for DSD was in part due to a negative reaction to “Intersex” by parents, who felt the word implied a third gender which contradicted their desire to raise a child according to the gender binary (Reis 2009:155). Another noted grievance was that “Intersex” was associated with sexual orientation (Reis 2009:155). The understanding appeared as though relating these conditions back to biological sex inadvertently related to gender and sexual activity. The way sexualities in America are described make gender and sex inseparable. Sexualities indicate what one does (sexual) with a type of person (gender). However, the term Intersex itself did conflate identity with sexuality, but rather the social anxieties of marriage and

homosexuality in the early centuries did. This indirectly demonstrates the same social anxiety: that as a society we would now have to question assumptions about sex and gender.

The fear of association between sexuality and atypical conditions are also apparent in the phrase Disorders of Sex Development. “Disorder” itself is another contradictory and demeaning word that implies something needs to be fixed (Reis 2009:156). Different or atypical conditions are put under a brushstroke of ableist wording (Reis 2009:156). Bodies that deviate from the norm are socially ostracized and “othered,” that follows an “us” versus “them” mentality. Ableism calls on pity and condescending attitudes that view differently abled people as inconveniences; thus, the new phrasing undermines activists’ main argument that different sex anatomy does not require cosmetic surgical and/or hormonal correction (Reis 2009:156). DSD does however bring attention to a much needed correction to health practices. Some argue that DSD will bring about more “patient-centered care,” where the ones most affected have an intricate part in their own bodily and mental health, rather than granting physicians the ultimate authority (Reis 2009:159). Physicians and other medical practitioners are still people who are influenced by the culture of their society. To assume as “scientists” they would be purely objective is wrong, as they can also respond to intersex patients based on cultural preconceived notions rather than actual health needs. Even now, physicians refer to Intersex/DSD people as hermaphrodites reinforcing the very stigma contemporary activists fight (Reis 2009:155).

The terminology used to describe the experiences and realities of atypical sex is still debated; therefore I use both terms in respect to different Intersex/DSD communities. Others have rephrased DSD to abbreviate for Differences of Sex Development and Divergence of Sex Development (Reis 2009:160). How we choose to describe our lives reflects on our values and social hierarchies. Words alone can be stigmatizing or carry misunderstandings and stereotypes.

Intersex/DSD people are a complexity in their multiple categories and a reminder of the beautiful, unpredictability of nature. These conditions are abnormal because as a society we choose to see and label them that way; their very existence indicates that they are in fact part of nature and thus “normal”. Our culture predicts how we react and outlines the ways in which we can respond. “As the scholar Suzanne J. Kessler declared, “Gender ambiguity is ‘corrected,’ not because it is threatening to the infant’s life, but because it is threatening to the infant’s culture” (Reis 2009:157). I would argue the debate on vernacular and the push for surgical practices hinge on America’s conceptualization of sex and gender. Despite medical and governmental pressure to enforce a binary, nature itself will not comply with our basic, social whims. This push for a binary also translates into expected social norms, such as how one is supposed to engage in sexual activity. The Western gender binary suggests that women are supposed to be penetrated vaginally. Such social norms can influence the ways in which doctors engage in surgical practices, such as genitoplasty.

Genitoplasty and Sexual Satisfaction in the Contemporary West: U.S. & U.K.

How our society has come to understand biological sex and gender affects perceptions about sexuality. It is then vital for physicians to consider the multiple complex functions of sexuality and how patient, non-consensual surgeries can influence a very personal aspect of a person’s life: their ability to have sexual satisfaction. Thus certain sexual function should be considered, such as sexual ability and desire. These factors include, but are not limited to erectile/arousal dysfunction, performance anxiety, and orgasmic capability (Woodhouse 2004:54). It cannot be determined from infancy of childhood the extent of a person’s sexuality, especially if the risk of depleting nerve stimulation is not explained to either parents or patient. Even non-surgical practices can be extremely invasive, such as hormonal treatments, which

“influence all phases of the sexual response cycle and [have] an influence both genitally and neurogenically” (Woodhouse 2004:55). The United States is infamous for its lack of healthy communication about sexual practices well into the years of the early 2000s. Thus, intersex/DSD individuals who have had surgical procedures (without knowing) may feel ashamed for different puberty developments, and/or may not know where to find resources on how to understand the scope of their own sexual possibilities. Assessing the quality, not just the appearance, of intersex genital procedures should be integrated.

Most surgeons in the U.S. and U.K. use female genitoplasty simply because a vagina is deemed easier to construct (Woodhouse 2004:57). These surgeons ultimately don't analyze bodily aspects such as the ability to lubricate and erectile functions (Woodhouse 2004:55). This consequently hinders the possibility or knowledge of being able to experience pleasure. There has yet been an ideal substitute for the standard female vagina (Woodhouse 2004:60). In other cases in which the clitoris is seen as larger than average, surgeons will see to it that the clitoris has a size reduction (Woodhouse 2004:60). The clitoris is considered vital for people with female bodies to achieve orgasms, hence the emphasis to preserve the clitoris (Woodhouse:58). Since clitoral preservation is not seen as vital, it makes one question then why the focus of physicians is on the appearance of the genitals, and what follow up assessments determine is a successful vaginoplasty. Woodhouse explains that “Some follow-up on vaginoplasty has been limited to assessments of patency, penetration and fertility without considering the quality of the sexual experience. Papers refer to the vagina being ‘satisfactory’ without saying to whom it was satisfactory or by what means satisfaction was measured” (Woodhouse 2004:57). This statement implies some of the general assumptions made about female sexuality.

One such assumption being that penetration alone is enough for sexual satisfaction, and while this may be the case on a micro level, it is important to assert why penetration is seen as more important to experience than the clitoris. Not all vaginoplasties result in clitoral reduction, but the emphasis on penetration may align with expected gender roles: being that the person with the vagina is dependent on the penetrator; or rather quite bluntly, that women need penile sex in order to be sexually satisfied, typically by a man. This notion can be further explore when considering that genital surgeries rarely are completed in one procedure (Woodhouse 2004:58). Such procedures can result in narrow vaginas that are subjugated to repeated self-dilation which can cause great discomfort (Woodhouse 2004:60). Self-dilation can take over the course of several months and even once the dilation is complete (the vaginal length reaches 10 centimeters) the patient would have to continuously use dilatation molds when not having intercourse (Woodhouse 2004:60). One can see the maintenance required for vaginoplasty that is repeatedly imposed on intersex people with ambiguous genitalia. There should be information about engaging in sexual intercourse with the genital form the intersex person was born with, to better give options on which course of sexual practices the person would want to engage in. It is not for society to tell people what persons are supposed to enjoy sexually in terms of bodily autonomy. There is no way to predict how a person, Intersex/DSD or not, may want to participate in sexual activities. It is then very important that all the risks associated with genitoplasty be explained with alternatives presented to the patient. The parents nor the physicians should be allotted with the responsibility of assuming the sexuality of a person, that decision should rest solely with the effected person. The dialogue about sexuality is not solely regulated to the medical field; conversations about sexuality are now more accessible with new technology, such as the internet. People have been able to ask questions and find representation

in small communities. Media is an agent of socialization and can help shape new perspectives about taboo or general misconceptions. Larger media sources, like television for example, are beginning to include topics about intersex conditions. MTV for instance has showcased an Intersex character in a new show targeting teens and young adults.

Intersex/DSD in Contemporary Television: MTV 2014

MTV, a popular television channel featured a new series called “Faking It.” This show revolved around two teenage girls who pretended to be a lesbian couple for social popularity. This show has been considered groundbreaking due to one of the characters (the protagonist’s stepsister) revealing herself as intersex (Anderson-Minshall 2016). The stepsister is named Lauren and experiences a “coming-out” process, which in turn educates audiences (Anderson-Minshall 2016). Lauren’s development as an intersex person was inspired by the writers of the show, one who was also intersex. As a result of the show, other people who worked in the media “came out” on MTV as a form of awareness, such as former animator Emily Quinn (Anderson-Minshall 2016). Quinn animated for Cartoon Network, a popular television channel geared towards children and pre-teens. Her work with the company made her quite well known, and that very popularity she has generated can help further spread her influence on intersex awareness. Most importantly, Intersex/DSD people are often rendered invisible, which can contribute to the shame placed on these conditions. Quinn has left her job as an animator to work for interACT, an intersex awareness organization, which has hinted on possible future reality shows. She has also developed an online series on YouTube called Intersexperiences about her conditions (Anderson-Minshall 2016). Quinn argues such representation will normalize intersex identity, utilizing media for its large platform and education on different experiences.

Media already contributes to social institutions and helps shape people's perceptions. Using media as a form of awareness will normalize the diversity and reality of human experiences. Some intersex/DSD people will go an entire lifetime not realizing or being aware of their conditions, especially if they have chromosomal differences (Anderson-Minshall 2016). It is important to normalize atypical conditions so that those affected can have access to the resources they need, whether mental, medical, and/or physical. In one scenario, a self-identified intersex person was told their condition was so extremely rare that they wouldn't meet another person like them (Anderson-Minshall 2016). Such misinformation, whether intentionally or not, encodes a sense of silence, that because one's conditions is so "rare," they need not look for resources or talk about their condition. Misinformation also ignores reality. There are actually more people with intersex/DSD conditions than Jewish people in the world (Anderson-Minshall 2016). Also, one in one hundred births deviate from the standards of male and female body types (Intersex Society of North America).

The conversation in general shouldn't be based on how many people with Intersex/DSD exist, but rather how do we as a society react and provide care to these individuals. Once these conditions are acknowledged, the next steps should be which forms of healthcare do they need, which procedures are available to them, and who can they contact if they would like to know share their similar experiences. None of these actions will be pursued if we deny Intersex/DSD people an understanding and awareness of their own bodies. The first step to bodily autonomy is being aware of your own body.

METHODOLOGY

Case Study

My study was a netnography on one Facebook group. I used Facebook because it is a popular media platform used worldwide with 1 billion active users (Facebook Newsroom). I specifically looked for Facebook groups that have 'Intersex' in the title. Intersex is a popular word used to describe sex characteristics that are neither male nor female; thus this term might be more commonly used, and therefore garner more search results. I acquired 11 intersex Facebook groups, and then downsized to a singular case study on a private group called Friends and Families of Intersex People. The group refers to its members and conditions as intersex, not DSD, thus the term DSD is neither used during data collection nor analysis. Friends and Families of Intersex People (FFIP) was created in May of 2014. This group consisted of 61 members, not including myself, by November 2017. Since this is a Facebook platform, the total membership number can change sporadically over time, as people join and leave the group; hence some posts may have more views than the current number of total members. The general demographics such as age and race were not collected in my data to further reassure anonymity. Also due to the constant change of members, the demographic information would not stay consistent. Members will be referred to as 'they, them, or their' in order to remain gender neutral and reinforce further anonymity. Some limitations were: inconsistent demographic information, the lack of responses from members within the group, and no surveys or interviews were conducted to gain direct responses from the people being studied. The research questions being pursued were: What topics do FFIP address? How does FFIP bring awareness to their cause? What forms of advocacy does FFIP include?

Data Collection

I used complete observation to collect data, thus I did not participate in the group in any way. I analyzed 22 posts. The posts were published over the span of 11 months, during 3 years: 2014, 2016, and 2017. There were 9 posts collected from 2017, 8 from 2016, and 2 in 2014. I only analyzed 2 posts in 2014, because these were the very first posts the group published after its creation. Data was not collected during 2015 to keep the data more contemporary and for my time sake purposes. There was frequent inactivity in the group, as posts would be created weeks, if not months in between; for example, there were only two posts in August 2017 with the next post then being created in September 6, 2017.

For the analysis itself, I wrote a basic overview of each Facebook post I: I took note as to how many people reacted to a post, how many people viewed a post, if there was a comment on a post and if so what that comment was about, what day, month, and year the post was made, and finally I categorized the posts into themes. I created 6 themes: LGBT+, Education, Community Building, Multi-Media, Event, and Call to Arms. LGBT+: a post that made reference to the LGBT+ community or included dialogue about non-heterosexual relationships and/or sexualities. Education: refers to posts that seem to present specific information about a term or topic. Community Building: refers to posts that are either a) introductory; members introduce themselves to the group by revealing personal information about their identities or b) community based; posts that encourage dialogue and interaction among members. Multi-Media: posts that are composed of other outside media sources, such as hyperlinks to online articles. Multi-Media posts demonstrate the interconnected use of multiple platforms. Technology, especially social media, show the many steps that information is passed through. Typically in this group's case it's a 3 step process: original social media source to Facebook post to individual member.

FACEBOOK AS A SOCIAL OUTREACH AND ADVOCACY TOOL IN INTERSEX/DSD GROUPS

28

Event: posts that refer members to public, informative events. . Facebook also has a tab bar created on the group website with some categories such as ‘Events,’ ‘Photos,’ and ‘Files’ that give direct access to certain media references. Call to Action: posts that encourage a form of action, typically online based, to reach out to other people or communities as a form of activism. The total posts ascribed to each category are as follows: 6 posts pertained to LGBT+, 5 were Educational, 10 were based on Community Building, 9 utilized Multi-Media, 2 were Events, and 1 was a Call to Action. Posts often intersected between multiple categories, for instance a post could be about an event that was related to the LGBT+ community; however, the total count is based on how many times each category was referenced individually, thus the counts are not based on combined posts. A sample of the data appears as such:

- d. Member makes a post a screenshot about another person who wrote hateful comments towards intersex people - august 8, 2017
 - .Poster mentions trying to inform the employers about the hateful person's words
 1. A call to action (post trying to encourage other members to participate either in discussion, an event, or specific actions as a community)
 - i.Links to article comments were based on: Vice from same post before
 1. <https://www.facebook.com/VICE/posts/1779284832104767>
 2. Liked by one, seen by 14
- e. A member poster posted about their specific conditions and appears to be asking for assistance on what the name of their condition is July 4 2017
 - .More a personal, informative post
 - f. Shared “Welcome to OII-UK...” article (<http://oiiuk.org/>) - July 20, 2017
 - .Platform to spread info about other groups/organizations
 1. Seen by 16 members, ‘liked’ by 2, ‘loved’ by poster

Online communication between members

Members of this Facebook group did not actively participate in active group discussion by commenting on each other’s posts. Most of the group members responses were based on Facebook’s emoji, post react system. Emojis are “any of various small images, symbols, or icons used in text fields in electronic communication (as in text messages, e-mail, and social media) to

express the emotional attitude of the writer, convey information succinctly, communicate a message playfully without using words” (Merriam-Webster). This Facebook system consists of a group of 6 symbols that indicate a person’s digital reaction to a post or comment. The symbols are a thumbs up to indicate a Like, a heart to indicate one loves the post, a laughing emoji face called Haha, an open mouth emoji called Wow, an emoji with a tear drop called Sad, and a red-faced emoji called Angry. These emojis were the core form of communication among the study group. Members were more prone to ‘react’ than comment to each other’s posts. Facebook also shows how many members viewed a post, regardless if they have commented or reacted to it. Whenever I viewed a post it would add to the viewing number, therefore when I reference a viewing number, it will discount my own. Members were more likely to look at a post rather than interact with it, for instance one post garnered 23 views, but only 6 likes.

However, there were cases in which either members or administrators would leave a comment to a post. There were a total of 7 comments. Two comments were on community building type posts. One in 2016 was a response to another member who shared personal information about their conditions and received a comment as a welcome from an admin. The other was praise for a scenic photo in 2014. Administrators were more receptive to comment and directly interact with people who talked about themselves. I perceive this as a way to engage in more open discussions, as administrators would then share personal information about themselves. Both types of comments create a sense of community by showing appreciation and making a form of familiarity among each other. Having typed responses to posts may encourage posters to participate more, while demonstrating to other members the possibility of a friendly, shared space. The scenic photo, unlike the personal informative one, fell under the Multi-Media category, as the response was directed towards a shared photo. The post that garnered the most

comments was also a part of the Multi-Media category as it was an interactive document that listed out various intersex conditions. The document was originally written by an administrator, which shows that the admins are interactive in and outside of the Facebook group and can use the Facebook group as a means to integrate their work. The document could be found under a tab named 'Files' on the group, making it easier for members to find and access it. There were 4 comments on this post, in one instance; a member recommended adding conditions as they did not find their own condition listed. Another member shared a story about a negative, medical process they experienced. Overall one can see how certain posts can have more impact, especially as the document post effected a majority of the members as it relates to their lives. Members may feel more willing to make comments if the post directly relates to them in some way.

Context of Case Study: Friends and Families of Intersex People

One of the administrators mentions that they started the group on behalf of their late wife (who is intersex), so that the late wife could get help and information about their condition. The group since then has an updated mission statement as of October 2017. The statement says

Friends and Families of Intersex People:

Is a peer run support and advocacy group for friends, family and significant others of intersex people and the intersex people they love to talk openly in a safe and private environment. We give support, educate, advocate, and make it clear to intersex people and their families that they are loved. Support: we're a place that people can reach out to that they are not alone and they will be...respected. Education: people can share their knowledge, information and resources to people inside and outside the group. Advocacy: offer a public voice to stand up for intersex people and their families.

The group clearly presents their purpose with an outline and how the online group contributes to each category. The purpose of the study was to see how this group implemented actions to fulfill those categories. On first notice, the group integrates general and personal

support for its members, along with advocacy. In this way, the group can remain as a support system, while also addressing things that are considered pressing issues. An example of this intersection occurred in August 2017, when a member made a post with a screenshot of another person's hateful comments toward intersex people. The 'hateful' person was not a part of this group, but was someone making a comment in response to a Vice article on Facebook. A member of the group FFIP then obtained basic information about this person, such as their name and where they were employed, then asked other group members to join them in reporting the hateful person to their employer. This posting and the members' reactions fall into my Call to Action category, as the original member tried to insight anger and have other members do things outside of the group as a form of response. The support part comes from the member expressing their feelings and trying to use this post as a means to express solidarity against verbal harassment and prejudice. This post is also an example of how posts can qualify for more than one category, as this post falls within my Call to Action and Community Building post, it would perhaps also fit with FFIP's definitions of Support and Advocacy. Other posts tend to follow this pattern of fitting multiple categories, thus showing the group's constant entanglement of support, education, and other aspects to appeal to more group members.

Self-Identification as Intersex and Other Terms

A key point then in studying and understanding intersex conditions, and those who have them, is to first explore how these people view themselves. Intersex conditions alone may not incline someone to identify as an Intersex person. The term 'intersex' itself is modern and thus may not be embraced by everyone who biologically qualifies as having those conditions.

Although Hermaphrodite has been considered a slur, some members would self-identify as such.

In one such case in March 2016, a speaker at a non-binary event said they found information

FACEBOOK AS A SOCIAL OUTREACH AND ADVOCACY TOOL IN INTERSEX/DSD GROUPS

32

claiming hermaphrodites to be mystical creatures, and thus reclaimed the slur to portray themselves as mystical. One post describing intersex conditions also has terminology with the word hermaphrodite included, such as the term True Hermaphroditism, which one of the administrators defined as requiring “the presence of both ovarian (female) and testicular (male) reproductive tissue. (Anonymous). Hermaphrodite is a word still used within the medical community, so despite being labeled as a slur by some, it may still be used as an identifier due to the traditional use of the word. Interestingly enough, hermaphrodite was associated as human myth, as it has not yet been possible for a mammal to have two fully reproductive sex organs. The term then can be misleading to those not within the intersex or medical community. Overall, the terminology associated with intersex conditions shows a rift between the intersex and medical institutions. In the U.S. the medical community is revered as a place of scientific objectivity; however, the ways in which the medical world understands the body is highly influenced by the mainstream culture. This in turn reflects on how intersex people view their own bodies and the terms in which they use to describe said bodies.

Within the same post, another intersex condition was labeled Timing Defect, which definition was “if all of the proper stages of normal male sex differentiation occur, but the timing is incorrect by just days, errors may arise. The occasional outcome in a 46, XY individual with this timing defect is ambiguous external genitals” (Anonymous). The language used in this definition can be seen as stigmatizing language, describing the body as wrong and a deviation from normalcy. It is interesting the condition is not just labeled as ‘ambiguous external genitals,’ but rather as a condition based on the timed development, assuming from the release of certain hormones. The word ‘error’ for instance implies a concern, and a deviation from what was supposed to happen. Humans have biodiversity, so to insinuate a physical deviation that does not

harm the person is incorrect, limits perceptions as to what human biodiversity can entail and should look like.

Describing intersex conditions as non-proper can also insinuate an ableist view on intersex bodies and people. Negative associations can possibly be internalized, as intersex people have expressed feelings of shame from their bodies in previous studies. Identifying something as non-normative is not perhaps problematic in itself, but other connotations can quietly suggest how the general public is supposed to view those conditions. The group has attempted to establish its own vocabulary to refer to themselves and other. The one term that the group appears to have coined itself is ‘herms,’ which appears to be a gender-neutral pronoun, specifically for infants or non-gendered children; for instance a member had stated that since there is “no certainty of a baby’s gender identity, babies should decide for herms-self what gender identity and what surgeries to have or not have” (Anonymous). American society does not currently have an established ‘third gender’ option, thus this group has developed its own vernacular to cope with the U.S.’s linguist limitations. The language that we have can also be limiting if it does not adequately portray or explain the real conditions of human lives.

Transgender Identity and Integration into Intersex Identities

Another main aspect throughout the study besides advocacy approaches was the integration of LGBT+ topics and an intersex identity. Intersex should not be equated with gender or sexuality, as it is a biological condition. Society has however, identified certain biological conditions as having social meaning, such as the assignment of secondary sexual characteristics to gender, such as facial hair. The group has mentioned to focus on intersex peoples and not gender identity, yet gender identity has become a focal point in group discussions. The first mission statement from the group in 2014 distinctly mentioned that transsexualism was not an

intersex condition, but rather a “gender identity disorder or gender dysphoria” and that anyone looking for support for transsexualism should seek elsewhere for proper support (Anonymous). It was unusual to see the term transsexualism used, as that word has been deemed as a slur by some in the LGBT+ community in the 21st century. This brings a focus on common vernacular and how the use of certain terminologies can appear as hostile, especially in the case of certain words being used as slurs. Although the intention of ‘transsexualism’ instead of the more preferred term transgender is not clear, there is an assumption being made by the group about how people might perceive intersex and gender. Since American society does not widely represent intersex conditions, the general public may be tempted to equate intersex and transgender as the same. This shows the unclear relations between gender and biology, since the general assumption follows the theory of gender essentialism. FFIP then felt inclined to make the distinction and reinforce the purpose of the group’s target audience. Interestingly, FFIP during its creation did not express a desire to participate in discussions about gender and sexuality, due to the focus being on intersex itself.

It is also important to note that the group referred to transsexualism as a gender disorder. As a support group, it is vital to destigmatize the intersex identity so that members may feel more empowered as individuals, and then as a collective. To then identify another group as a disorder brings to question the understanding between gender and anatomy within the group itself. Other intersex advocacy groups were dismissed as people with identity disorders by major medical establishments, in order to dismiss and delegitimize the importance of inter people’s concerns. FFIP use and definition of transsexualism then are examples of how the oppressed are capable of continuing the ideologies and defenses of the oppressors, intentionally or not.

FFIP shifts in terms of gender representation. The updated mission statement in 2017 takes a different, more inclusive approach: “Intersex is not the same as transgender (people who identify as a different gender than they were assigned at birth) because intersex refers to biological sex and transgender refers to gender identity. But some people happen to be both. [FFIP] welcomes respects and embraces people of all sexual orientations and gender identities” (Anonymous). Over the span of 3 years, FFIP has become more articulate in describing gender differentiation. Their revised explanation of transgender specifically mentions being “a different gender than they were assigned” rather than referring to a binary, such as claiming transgender people are the ‘opposite’ gender (Anonymous). This subtly in language changes the overall perceived tone of the group. This is reflected in other gender identity based posts made by members.

As previously mentioned, members would sometimes create introductory posts about themselves, such as where they are from, and typically what specific intersex condition they have. Eventually, gender and sexual orientation became a part of such posts. One member for instance in 2016 mentioned they were MTF (Male to Female) transgender. MTF terminology is also indicative of the gender biology association, as the phrase does not explicitly indicate sex assignment surgery. Male and Female are biological categories, both their assumed gender implications is another key example of gender association in the U.S. Society deems gender an intricate part of one’s identity, hence it is understandable why FFIP members included their gender and sexuality while introducing themselves. For this member being intersex and a transwoman was an intricate part of their identity. An assumption may be that one has to be a man with a male body in order to transition into a woman, but since the U.S. does not centralize a biological dialogue outside a binary, having an intersex body does not automatically make a

person genderless: occasionally the focal point to an intersex person's gender identity is determined by what gender they are assigned by either the parents, the physicians, or both.

A member sharing their gender and sexual orientation information can also heighten a sense of community building. Other may feel encouraged to also share such details. These details help introduce a platform to then integrate gender and sexuality topics into the larger dialogue of having an intersex body. One aspect of that dialogue then can be about the intersection of prejudices a gender nonconforming and/or non-heteronormative intersex person can experience.

Transphobia and homophobia used against the intersex identity

Throughout the year 2016 and into the year 2017, members shared more information about gender and sexuality, in some cases even sponsoring or recommending events that integrated these topics with intersex people. As gender and sexuality became more expressed by intersex individuals, LGBT+ issues became more integrated outside the scope of just a member's identity. One member in October 2017 praised the intersex community for its role in "the formation of the modern day [intersex] activist, bodily autonomy, genital autonomy, gender equality, LGBTQIA pride, and LGBTQIA equality movements" (Anonymous). Another post also addresses North Carolina's bathroom law in 2016, which was meant to bar transgender people from using the bathroom based on their gender association. The member who shared the post claimed that the law enforces people with XY chromosomes to use the men's room. In this scenario, politicians and lawmakers are trying to enforce social constructions with 'hard science.' This hard science is based on biological assumptions which associate certain physical traits with gender perceptions, which are at odds with intersex bodies (some intersex conditions include not having neither XY nor XX chromosomes). Here, there is a direct correlation with the LGBT+ movement itself, demonstrating how they intersect.

Although intersex people may face different forms of oppression, society's correlation between biology and identity has made the intersex community face similar oppressions as those in the LGBT+ community. The intersex community has also received direct homophobic and transphobic comments from other groups and individuals.



Here is a screenshot a member posted showing some of the profane comments directed towards intersex people. It appears this person is conflating transgenderism and homosexuality with intersex conditions. An intersex body defies the western mainstream notion of a sex binary. The commentator uses pre-existing prejudices to cope with intersex bodies not complying with their perceived notion of identity and anatomy. The commentator then suggests that gender nonconforming people are responsible for upsetting the gender binary. The commentator seems unable to understand that intersex bodies exist regardless of gender, and that intersex people's existence alone does not comply with the idea that only the penis and vagina (and no other forms of genitalia) have existed for thousands of years. A lack of recognition from the medical community, and representation allows for misconceptions to fester into dehumanizing prejudices.

Friends and Families of Intersex People Use and Definition of Advocacy

The lack of general knowledge in the U.S. society's mainstream about intersex conditions, allows for misconceptions about intersex bodies and identities which have harmful consequences. Online spaces like Friends and Families of Intersex People, demonstrate how a

FACEBOOK AS A SOCIAL OUTREACH AND ADVOCACY TOOL IN INTERSEX/DSD GROUPS

38

collective dialogue can help spread information and establish agreements on what the community constitutes as issues. One such issue is the use of ‘corrective’ surgery on infants. This surgery intends to ‘correct’ a child’s genitalia to ‘match’ the picked gender assignment. Members have posted about the surgery as a human right violation each year since the group’s creation. Most surgery based posts were Multi-Media: the posts tended to be articles. Members who posted about corrective surgery argued against the legality of such medical practices. One member made a post referencing Canada’s laws on body alteration. The Canadian law claimed that mutilation based on sexual appearance should not be performed, specifically female mutilation, which consists of the removing of the clitoris. This same general notion also applies in the U.S., where the law states that female genital cutting should not be performed “as a matter of custom or ritual,” yet these surgeries are performed mostly for aestheticism than to protect the child’s health (Legal Information Institute). Members then argue that these laws should include intersex conditions, so that intersex people can make consensual choices about their own bodies and health. The group members’ frustrations indicate the lack of protections they have within the legal system. Even outside the FFIP group, intersex organizational websites have cited nonconsensual surgery as one of the most invasive abuses intersex people face. There appears to be limitations as to who such laws applies to, and the vague terminology used to make these laws create loopholes in which the medical community can impose its own notions of gender and anatomy onto an infant or child. A post in August, 2017 referred to the Scientific American Article, in which a member was displeased with the phrase ‘Disorder of Sex Development,’ arguing that the phrase “is both scientifically inaccurate and harmful. No minority should be referred to as a disease. Intersex people are people. There is nothing wrong or bad about having a body which is not clearly male or female. And calling intersex people a disorder gives a green

light to doctors and other health-care providers to do nonconsensual and unnecessary surgeries on intersex babies and children” (Anonymous). It appears the major concern from this member is that certain terms can enforce current, unethical surgical practices. The member then continues to suggest that such medical practices are a form of eugenics, thus other online members should contact the authors of the article and demand an apology and retraction. The post and the reaction from group members show how FFIP utilizes dialogue to possibly inspire action.

There have also been cases in which group members have participated in events or in other media platforms to talk about their experiences as intersex. This form of action follows FFIP’s definition of advocacy: “offers a public voice to stand up for intersex people and their families” (Anonymous). A group member appeared on a radio show to discuss the use of corrective surgeries and its effects on intersex people. The radio host then proceeded to question the intersex guest about how their body looked like as a child. Other members of the FFIP showed dissatisfaction with such a question, as it was seen as invasive to the guest’s privacy. Such questions also show society’s fixation with ‘otherness’ and the appearance of atypical bodies, rather than focusing solely on the oppression and lives of the intersex people themselves. Nonetheless, the online group functions to demonstrate what members have done and how other members can join by sharing the information with others, learning about the media event itself, or in the cases of literal public events, members can then attend them. This online group since the data collection did not include other forms of advocacy more associated with activism such as protests or petitions. The group’s activity does show the foundations of advocacy with its open dialogue and encouragement to participate. In this way, the intersex community can feel as though they are a part of a larger collective and find ways to use their agency. Online groups can

FACEBOOK AS A SOCIAL OUTREACH AND ADVOCACY TOOL IN INTERSEX/DSD GROUPS

40

help communicate with its members the types of advocacy individuals can engage in. Having a range of advocacy options can help members adapt certain actions into their lives.

CONCLUSION

FFIP is only one such group on Facebook, and the internet in general, that uses social media platforms. Different Facebook groups have different mission statements, which establish the groups' goals. For intersex groups, expressing a shared identity is intricately linked with being in a political space (political in terms of a power dynamic). As an oppressed group, their embraced identity as intersex people and as an established community defies the very notion of a gender-sex binary. Based on the data, the main themes FFIP addressed related to gender & sexuality and autonomy over surgical practices. The surgical practices come from the U.S.'s pressure to enforce a gender-sex binary. If a body does not match according to this ideology, then that body is labeled as a disorder, unnatural, and seen as needing to be 'fixed.' Gender then becomes the central point to society's response to intersex conditions. Arguments that intersex people be able to choose their own gender identities goes against cisgenderist ideologies. The mainstream U.S. assumption that bodies only exist within a binary develop into nationwide policies that then influence the individual and what level of agency they have.

FFIP is an example of how macro level socializations (gender) affect the everyday responses of people and whole institutions (medical establishments). Support groups are created based on a collective need for communication and for the sake of a safe environment to express oneself. Facebook functions as such a tool, as it provides access to millions of people, and thus increases the chances of networking with people across the globe. Such networking has also contributed to how online groups change the course of their discussions. FFIP in its creation in 2014 did not include as much dialogue as it did in the years of 2016 and 2017. How members interact with each other can change the overall tone and networking of a group. As people included gender into their comments, there appeared a shift towards more gender inclusivity. The

aspect of gender is very important to this study, as issues pertaining to the community were based on how the general population and doctors treated intersex people. Since the 20th century, attitudes towards intersex people were based on gender assumptions and behaviors of the time, including a fear of homosexuality.

Homophobic ideologies shaped medical treatments geared toward intersex conditions. The fear that intersex people could engage in coitus with someone of the same sex began the association of intersex people and the LGBT+ community. There was also a legal fear since some intersex conditions allow a person to be seen as neither a man nor woman; the law would be unable to persecute intersex people, if they can argue that they are engaged in heterosexual behaviorisms. This brings into question the ability of laws to keep citizens safe and who is able to create such laws. Female mutilation for instance is seen as an issue pertained to standardized female bodies only, thus allowing physicians to legally avoid the law against genital cutting relating to intersex conditions. Such views have adapted so that in the 21st century the general misconception is that people who are intersex are inherently not heterosexual or transgender. Thus intersex issues have intersected with LGBT+ issues, more so for intersex people who identify as non-heterosexual and/or transgender. Future research should continue to evaluate how the internet has bolstered a platform for advocacy and awareness. Research should not minimize the role and importance of gender ideology effects on the intersex community, while also respecting the gender identity of intersex people. Perhaps more ethnological studies should be implemented to understand how intersex people see themselves, their communities, and their forms of agency.

Bibliography

- Anderson-Minshall, Diane.2016. "Are We Witnessing the Birth of TV's Intersex Liberation?"
Advocate (Issue 1087): p60-62.
- Anderson, Sharon.2015. "Disorders of Sexual Differentiation: Ethical Considerations
Surrounding Early Cosmetic Genital Surgery." *Pediatric Nursing* Vol. 41 (Issue 4):p176-
186.
- Anonymous. Friends and Families of Intersex People. Retrieved Dec 5, 2017.
- Berenbaum, Sheri.2006."Psychological Outcome in Children With Disorders of Sex
Development: Implications for Treatment and Understanding Typical Development"
Annual Review of Sex Research. Vol 17 (Issue 1):p1-38
- Bergner, Erin M. 2014. "Reading Between the Lines: Intersexuality in News Media, 1993-2013."
Conference Papers- American Sociological Association. P1-34
- Blumer, Markie, and Ansara Gavriel, and Courtney Watson. 2013. "Cisgenderism in Family
Therapy: How Everyday Clinical Practices Can Delegitimize People's Gender Self-
Designations." *Journal of Family Psychotherapy* Vol. 24 (Issue 4): p267-285.
- Dictionary. "Consciousness-raising." Retrieved May 8, 2017.
(<http://www.dictionary.com/browse/consciousness-raising>)
- Dictionary. "Tomboy." Retrieved May 8, 2017 (<http://www.dictionary.com/browse/tomboy?s=t>)
- Douthirt Cohen, Beth. 2012. "Reimagining gender through policy development: the case of a
'single-sex' educational organization." *Gender & Education* Vol.24 (Issue 7): p689-705.
- Facebook Newsroom. 2017. "Statistics" Retrieved Nov. 15, 2017.
(<https://newsroom.fb.com/company-info/>)

FACEBOOK AS A SOCIAL OUTREACH AND ADVOCACY TOOL IN INTERSEX/DSD GROUPS

44

Fox, Karen. 1986. "The Measurement of Issue/ Advocacy Advertising Effects." *Current Issues & Research Advertising* Vol. 9 (Issue 1): p61-92

Intersex Society of North America. "How common is intersex?" Retrieved Nov 21, 2017
(<http://www.isna.org/faq/frequency>)

Intersex Society of North America. "What is intersex?" Retrieved May 8, 2017.
(http://www.isna.org/faq/what_is_intersex)

Legal Information Institute. "18 U.S. Code § 116 - Female genital mutilation." Retrieved Dec 5, 2017 (<https://www.law.cornell.edu/uscode/text/18/116>)

Marija, Mija and Rozman, Klemencic. 2015. "DIFFERENCES IN THE PERCEIVED BENEFITS OF MEMBERSHIP AMONG TYPES OF SELF-HELP AND SUPPORT GROUPS." *Ljetopis Socijalnog Rada / Annual of Social Work* Vol. 22 (Issue 3): p351-370.

Merriam-Webster.2017."Definition of Emoji" Retrieved Nov.15, 2017. (<https://www.merriam-webster.com/dictionary/emoji>)

Migeon, Claude J. and Amy B. Wisniewski, and John P. Gearhart, and Heino F.L. Meyer-Bahlburg, and John A. Rock, and Terry R. Brown, and Samuel J. Casella, and Alexander Maret, and Ka Ming Ngai, and John Money, and Gary D. Berkovitz. 2002. "Ambiguous Genitalia With Perineoscrotal Hypospadias in 46,XY Individuals: Long-Term Medical, Surgical, and Psychosexual Outcome." *American Academy of Pediatrics* Vol.110 (Issue 3):p1-10.

Melby, Todd. 2002. "Intersex Interrupted." *Contemporary Sexuality* Vol. 36 (Issue 12):p3-6.

- Preves, Sharon E. 2003. "Hermaphrodites with Attitude: The Intersex Patients? Rights Movement and Clinical Reform." *Conference Papers- American Sociological Association* p1-19.
- Reis, Elizabeth. 2009. *Bodies in Doubt: An American History of Intersex*. Baltimore: Johns Hopkins University Press
- Rubin, David A. 2012. "'An Unnamed Blank That Craved a Name': A Genealogy of Intersex as Gender" *Signs: Journal of Women in Culture & Society* Vol.37 (Issue 4):p883-908.
- Rubin, David A. 2015. "Provincializing Intersex." *Frontiers: A Journal of Women Studies* Vol. 36 (Issue 3):p51-83.
- Schmader, Toni and Block, Katharina. 2015. "Engendering Identity: Toward a Clearer Conceptualization of Gender as a Social Identity." *Sex Roles* Vol.73 (Issue 11-12):p474-480.
- Schweizer, Katinka and Franziska Brunner, and Karsten Schutzmann, and Verena Schonbucher, and Hertha Richter-Appelt. 2009. "Gender identity and coping in female 46, XY adults with androgen biosynthesis deficiency (intersexuality/DSD)." *Journal of Counseling Psychology* Vol. 56 (Issue 1):p189-201.
- Vicari, Stefania. 2014. "Networks of Contention: The Shape of Online Transnationalism in Early Twenty- First Century Social Movement Coalitions." *Social Movement Studies* Vol. 13 (issue 1): p92-109.
- Woodhouse, C.R.J. 2004. "Intersex Surgery in the Adult." *BJU International* Vol.93(Issue 3): p57-65

FACEBOOK AS A SOCIAL OUTREACH AND ADVOCACY TOOL IN INTERSEX/DSD
GROUPS

46

Zhou, Yushu and Pinkleton, Bruce E. 2012. "Modeling the Effects of Political Information

Source Use and Online Expression on Young Adults Political Efficacy." *Mass*

Communication & Society Vol.16 (Issue 6): p813-830.