

## Negotiating Normality: Experiences from 3 Italian Patient Support Groups

### Introduction

In the world of biomedicine doctors and patients walk through linguistic and cultural mazes in search of explanations, solutions and care. One of the tools that patients increasingly use to have an active role in their care and to elaborate the meaning of what is happening to them, is patient run support groups. These groups increasingly use the Internet as their virtual home. As they negotiate biomedicine they blur the lines between experts and others. Whereas the antagonistic economic relationship between patients and medical structures obviates a certain consumer advocacy in the USA, the dynamics are different in a state-sponsored health system, such as in Italy, where official recognition of a syndrome is necessary for funding of care and institutional support.

Italy offers a high degree of access to state covered health care. In the 70's when the National Insurance Bill was passed, most care was free or subsidized (Cosmancini 1994). Since the late 90s, when a system of tickets was instituted, many hidden costs have entered the system. Accessing the care you want can be complicated, however, involving multiple referrals, and a battle against a paternalistic tradition (Macellari 2003). Patient-run support groups offer one strategy for impacting treatment and classification options.

As two Italian anthropologists separately studying patient run groups, we present our findings together in this joint paper in order to describe some of the current efforts of Italian patients to address medical protocol and identity issues in biomedical terminology. In specific, the groups we look at represent syndromes that have a history of ambiguity or disagreement regarding definition and care. In the period from 2006 to 2010, we respectively followed the development of the groups' websites, assisted group activities, from group meetings to negotiations with medical practitioners or legislative bodies, and collected individual interviews of active group members. What emerges from our research is the dance patient groups perform to be recognized as a valid voice in the debate surrounding their care, not necessarily contrasting medical professionals, but seeking what Michel Callon refers to as

“intégrer les différentes dimensions du débat pour aboutir à une solution “robuste”” [integrating the different dimensions of the debate in order to reach a “robust” solution.] (Callon 2001).

The three groups that we work with are all patient run and organized support groups that have varying alliances with institutions and doctors. They represent Asperger's syndrome -- Il *Gruppo Asperger* (Asperger Group), -- Androgen Insensitivity Syndrome, -- A.I.S.I.A., *Associazione Italiana Sindrome da Insensibilità agli Androgeni* (Italian Association Androgen Insensitivity Syndrome) -- and Klinefelter's syndrome -- Klinefelter Italia ONLUS (KIO). They operate within biomedical frameworks to varying degrees, initially braking the “I’m the only one” barrier, and offering information exchange and authority; addressing issues such as identity-politics, medical intervention and definition, research directions, health care subsidization negotiation, social relations, parental concerns and other related concerns. The groups all walk the fine linguistic line between syndrome and disease, and deal with the issues embedded in pathology as defined by statistical difference as well as the crossover of medical practice in the arenas of genetics, behavior and identity. In these regards medicine continues to have a significant role in the contemporary development of the norm as expressed by Foucault (1963) and many others.

We observed several themes shared among these groups: rejection of stigmatizing terminology, medicalization<sup>1</sup> of difference (Conrad 2007) and over-standardized care models, in conjunction with an acceptance of medical terminology and diagnosis resulting in requests within the medical context for more information, communication, research and treatment options. This position can be simplified as a quest for useful medicalization, that is: the use of medical techniques and terminology to achieve certain goals explicitly defined by the patient (Davis 1997), while at the same time contesting medicalization seen as solely normalizing or stigmatizing.

It is the nature of syndromes to beg the discussion of pathological read as wrong, versus

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<sup>1</sup> The process by which human conditions and problems come to be defined and treated as medical conditions and problems, and thus come under the authority of doctors and other health professionals to study, diagnose, prevent or treat.

pathology read as difference. It is our interest to show some of the ways in which these patient groups in Italy negotiate authority over care (also through recourse to experts and practices outside of Italy), in which both groups directly promote increased medical research while problematizing the flow of medical knowledge and discussion.

Asperger's syndrome is one manifestation within the umbrella category of autism. As with autism, it is characterized largely by an acute difficulty to interact socially and by the presence of intense and focused interests, which appear obsessive. Individuals diagnosed with Asperger's tend to be isolated, intensely concentrated on their activities, with a limited social life. The main difference from traditional autism is an average or higher than average intelligence. IQ measurement is part of the diagnostic process, using the Stanford-Binet or WAIS tests (Cianciolo and Sternberg 2004; De Carolis 2004; Gardner 1993).

Androgen Insensitivity Syndrome (AIS) and Klinefelter's Syndrome fall within the umbrella category of Intersex or Disorders of Sex Development (DSD). AIS is defined as an insensitivity to androgens which results in feminine external physical development (phenotype) in a person with XY chromosomes ("male" genotype). Partial Androgen Insensitivity Syndrome (PAIS) can manifest in "ambiguous" genitalia<sup>2</sup>, but generally the female gender is assigned. Klinefelter's represents the presence of a third sex chromosome, in the form of XXY, with generally male gender identity. None of these diagnoses were categorized as hermaphrodite or necessarily diagnosed at all before the increased medical interest in sex differentiation in the 18<sup>th</sup> century.

While Autism (Asperger's) and DSD syndromes have different histories and trajectories, they are both marked by two notable factors: 1) both diagnostic categories have strong implications for individual identity and perceived identity; and 2) both are marked by the tradition of medical pathology defined by deviance from the norm as opposed to expressed patient/individual complaints.

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<sup>2</sup> Thus, it can also lead to subsequent controversial early childhood irreversible genital "correction" surgery.

The groups navigate the desire to negotiate pathology guidelines, and therefore treatment. They often sidestep theoretical discourses such as the place of the divergent mind or body in a normative society, to address practical questions such as “what do I do now that my gonads have been removed?” or “how can I have positive social relations with those around me?”

Group	Year Founded	Approx. # Members 2010	Type of members in size order	Major goals	Major activities
Gruppo Asperger	2003	Around 400	1. Parents 2. Patients 3. Medical professionals 4. Friends	1. Social networking 2. Information exchange/publicity 3. Increase research	1. Mailing list/ Web site 2. Socialization 3. Recreation 4. Policy activism
AISIA	2006	Around 100	1. Patients 2. Parents 3. Medical professionals	1. Social support 2. Information exchange/publicity 3. Increase research 4. Policy change	1. Web site 2. Socialization 3. Medical conventions 4. Research participation
KIO	2004	Non-disclosed	1. Patients 2. Parents	1. Social support 2. Information exchange/publicity 3. Increase research 4. Policy change	1. Web site 2. Socialization 3. Medical conventions

### Patient-run Medical support groups

There are multiple ways that supports groups have been investigated in anthropology, sociology, and science studies, from Steven Epstein’s work on how AIDS patients and their allies contributed to the redirection of research and treatment protocol (1998), to Nikolas Rose’s article (2000) that addresses the sociality related to genetically predisposed syndromes. This followed the conceptual framework of bio-sociality offered by Rabinow, which addresses the socialization around a medicalized category. Adele Clarke argues that not just medicalization (defining a problem in medical terms), but bio-medicalization, that is technology centered medical reading of bodily experience and norms, is intensifying (Clarke et al 2003). Peter Conrad places patients in their role

as medical consumers as major players in the shifting nature of medicalization (2005).

In a state sponsored health system patients are not seen as consumers, and perhaps lose this aspect of economic negotiating power. When not seen as consumers, patient support groups can be seen with suspicion by medical practitioners, not only because of their occasionally antagonistic role in requesting changes in treatment protocol, but also because of their more general request for a more authoritative position in how to address the syndromes. Support groups have, on one hand, sustained accusations of promoting an eternal sick role or being representative only of unsatisfied patients<sup>3</sup> (Karkazis 2008), on the other hand they can also be seen by researchers as a rich source for collecting research data, stimulating collaboration.

Group members do not necessarily use the syndrome category as a primary identity; in fact, individuals within the groups relate to this issue of identity within diagnosis and self-diagnosis in different ways. Patient run medical support groups organize around a shared experience. Medical specialists can only have an indirect knowledge of the daily experience of the individuals diagnosed, experience which is precisely the terrain from which the groups gain their legitimacy, moving towards a “co-production of knowledge with specialists”. (Akrich, et Al. 2008: 14) In this vein, as seen in Maren Klawiter’s work with breast cancer politics (Klawiter : 232), patient groups, push specialists to inform them of *all* of the options available, so that treatment will match their individual needs within the spectrum diagnostic categories.

## Negotiation of definition

### The “Aspies”<sup>4</sup>

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<sup>3</sup>This position is often expressed by physicians at medical conferences in Italy. The idea is that satisfied patients do not seek out patient groups.

<sup>4</sup>The term *aspie* is used by people with AS in reference to Neurodiversity theory and has an identity function in opposition to “neurotypicals”. The term can also indicate, as in this case, people within the autistic spectrum defined as “high functioning”. In the course of this paper I use *Aspie* to indicate members of the Italian Asperger Group. Within the group most individuals define themselves as *aspie* without necessarily referencing Neurodiversity theory. Hans Asperger wrote about psychopathic autistics in 1944. Recent studies highlight how modern Asperger’s syndrome does not coincide perfectly with Asperger’s “discovery” (Nardocci 2003).

Gruppo Asperger was founded in Milan in 2003 by people interested in the syndrome for personal and/or professional reasons. As noted in its constitution, the group hopes to address the insufficient knowledge about this syndrome in the Italian scientific community. Despite being spread throughout all of Italy, the group's 400 members (increasing every year) are fairly united; they meet frequently to discuss their common experiences and communicate frequently by Internet, sending or posting information about articles, films or books on the syndrome.

Asperger's syndrome became officially recognized in 1992, when it was first included in the ICD-10 (International Classification of Diseases, 10<sup>th</sup> Revision). Two years later, under the name of Asperger's Disorder, it was also included in the DSM (Diagnostic and Statistical Manual of Mental Disorders) IV. Before this period people who are now diagnosed Asperger's could have had a large range of diagnoses, most often PDD NOS (Pervasive Developmental Disorder Not Otherwise Specified), High-Functioning Autism<sup>5</sup>, as well as the unofficial category of FLK (Funny Looking Kid) as Grinker notes (Grinker 2007:166). Asperger's syndrome is beginning to be known outside of specialized circles in Italy, due to a recent explosion of film and literature on the subject (Haddon 2003, Tammet 2006, Naes 2005, Balthazar 2007, Mayer 2009 among others).

Gruppo Asperger is currently the only group in Italy dedicated specifically to this syndrome, which unites Aspies, their friends and family. As emerged from the interviews and observed group communications, the main aims of the group seem to be to: 1) increase awareness of Asperger's syndrome with the aim to make behavior that is considered bizarre understandable, and not stigmatized; 2) offer practical and moral support for parents--exchange information about their children's personal lives as well as information surrounding disability law and the right to school support and discuss the various therapies available and their results; 3) increase moral support for persons diagnosed with Asperger's syndrome by creating opportunities for them to meet, to exchange

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<sup>5</sup> There is still much discussion as to whether there are two distinct syndromes or different levels of the same syndrome (Wing 1981, Frith 2003).

opinions and stories, and therefore help social interactions; 4) create events that are protected and specific to the needs of members so that Aspies have the possibility to interact positively amongst themselves (often during these events there are also psychologists present); 5) organize informative and interactive events for parents, for example, cycles of parent training seminars; and 6) create a team that can dialogue with the public administration.

In addition to the activities of Gruppo Asperger, there is also the LEM cooperative, founded in Milan by the members of the group, which aims to create work opportunities for people with Asperger's syndrome. The LEM cooperative occupies itself mostly with graphics, websites and such activities in which Aspies are considered to excel by members and researchers, and facilitates interaction with employing agencies and individuals. This idea of Aspies' innate skills is perpetuated in part of the group's imagery.

Along with LEM cooperative and also in Milan, a social center was opened in December 2008: *Spazio Nautilus* (Nautilus Space) is open not only to Aspies, friends and family, but to who ever would like to participate. The center has a café, a game room, a library and a comic library. There is also a conference room with a large desk and folding chairs that can also be used as a role-playing game room. The group in Milan meets once a week; on Sundays there are group games such as cards and board games, and twice a month on Saturday there are dinner and film nights.

In Rome, since December 2008, a local cinema club has hosted a cycle of films organized by Gruppo Asperger. The films are generally chosen by the Aspies, and before the film there is an aperitif that provides social opportunities. After the film, there is a discussion lead by the Aspies and some psychologists.

The decision of the board of directors *not* to limit the group to those officially diagnosed Asperger's but also to include those self-diagnosed is significant, and it indicates an elastic dialogue with official clinical knowledge categories. It is not meant as an opposition to canonic clinical knowledge such as the indications of the APA (American Psychiatric Association) or WHO (World

Health Organization). It indicates that the group wishes to leave interpretations open, capable of discussing the limits of diagnosis case by case. The interpretation of the diagnosis is considered subjective, also for the neuropsychiatrists called in to give an official diagnosis. The subjective aspect of diagnosis is a critical point of debate for some Aspies. Not everyone is interested in an official opinion of a diagnosis. A self-diagnosed member of the Milan group expresses this sentiment clearly, stating: “La mia diagnosi non ti sembra abbastanza autorevole? Credi che ne sappia di più uno che è pagato per sparar diagnosi sulla SA, o io?” (“My diagnosis doesn’t seem authoritative enough for you? Who do you think knows more [about Asperger’s syndrome], someone who’s paid to diagnose SA or me?”) (e-mail to author 1, April 20, 2009).

The practice of psychology in Italy is strongly marked by the actions of Basaglia and the Psichiatria Democratica (Democratic Psychiatry Movement), which struggled for a holistic vision of mental health patients and the eventual closing of prison style mental asylums (Basaglia 1973). However, these changes have become part of Italian history and are not directly referenced in the group, who often will look to English language literature that specifically addresses their issues. The actions of Basaglia and the changes in psychology opened the door for patients to negotiate their own diagnosis in Italy and have removed some of the stigma associated with mental health diagnoses.

Although the majority of the Asperger group members do not openly participate in epistemological or phenomenological debates concerning the definition and knowledge of the syndrome, the group was clearly united against the definition of the phenomenon and the proposed therapeutic solutions in the new 2008 legislative proposal regarding autism in Italy (Senato della Repubblica Italiana, 2008).

The Ministry of Health created a commission to study autism from April 2007 to January 2008. Even though the commission was informed by diverse experts and autism support groups, often in line with the psychological model based on the DSM-IV TR, the proposed law speaks of autistic phenomenon as an *epidemic* and a *social disease*, without stating exactly what they mean by these

terms. It notes that autistic phenomenon, without distinguishing among the various types, “rischia, se non contrastato in tempo, di assumere le caratteristiche di una vera e propria epidemia” (risks, if not controlled in time, assume the characteristics of a real and true epidemic) (Senato della Repubblica Italiana, 2008:1). Not surprisingly, the use of the rhetoric of epidemics, and its association with contagion, when speaking of a developmental disorder that may have genetic causes, was not appreciated by the group.

Another point criticized by the group was the manner in which the DAN! (Defeat Autism Now!) method, from the United States, that is highly biologically deterministic,<sup>6</sup> is positively referred to as the only example of an multidisciplinary medical approach. The DAN! method is referred to in the senate document as an important new American theory, while it is not seen as the most valid method in the United States. DAN! method supporters often also support the theory that links vaccination to the increase in autism. Grupo Asperger tends to support biological models that refer to genetics or neurology, but not diet or vaccination. Italy, in any case, has a lower level of childhood vaccination requirements than the United States<sup>7</sup>.

In 2009, the board of directors of the Asperger Group became involved with the Association FANTASiA (Federazione delle Associazioni Nazionali per la Tutela delle persone con Autismo e Sindrome di Asperger) [Federation of National Associations promoting the rights of persons with Autism and Asperger’s Syndrome]. These groups are trying to organize a meeting with the undersecretary of Health and distributed a document in which the position of the group is explained. Given the arguments addressed by the group, and their entrance into a public discussion of the implications of definition and diagnosis, a large portion of the document is cited here:

Above all we believe in the freedom to choose one’s treatment (stated in our constitution) and that each of us can follow the course they feel is best and satisfactory. There can be no judgment towards a family or individual who chooses one therapy over another, that’s the last thing one needs! [...] But one can’t “simplify” a complex thing. Scientific discoveries don’t

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<sup>6</sup> Italian DAN! literature cites American parents with simplistic biologically deterministic statements such as: “con l’olio di fegato di merluzzo è passato da 3 a 150 parole in 45 giorni” (“with cod liver oil [her son] went from 3 to 150 words in 45 days”) (Chirenti V. e Verzella F., 2005: 189).

<sup>7</sup> Mandatory vaccines in Italy are: Polio, Tetanus, Diphtheria and Hepatitis B.

always contain a cure, for example Rett syndrome and Fragile X (at one time classified as Autistic pathology) are genetically identified, but the cure has not yet arrived.

The final document of the National Discussion about Autism (in which, to tell the truth, supporters of DAN! also participated, but sporadically), which anyone can read on our website, also sustains that it is important to support research surrounding gastrointestinal problems, abnormal permeability of the intestinal wall, and other complicated metabolic alterations. Scientific research is therefore very important, but it needs to be free from conditions, it needs to try all the possibilities and subject itself to rigorous verifications. Instead the supporters of DAN! believe that their method is the solution, stop. That it works for all autistics, aspergers, hyperactives, with or without gastrointestinal problems. We invite everyone to investigate why it is important to form an individual opinion on the subject [...] without taking away from the need to support research on the methods advised by the scientific community.

In the end we would like to offer for reflection the words written by P., our vice-president and an individual with Asperger's Syndrome, about these issues: "One must criticize the use of the words disease and epidemic in the legal proposal, that lead one to think of infection, marginalization, witch hunt.

The autistic spectrum, especially the part that concerns us, is not a disease to eradicate from society, but of condition of life, a way of being, a different point of view on the world and other people, with its defects but also its virtues. I don't want to be "cured" nor do I want that one day all the other people like me disappear from the face of the earth, but I would like them to have the tools to use their gifts, to compensate their limits and to be accepted in their difference, not excluded. I know from personal experience that it can be done, I did it by myself with much difficulty, I could have done it earlier with the right help if there had been some. Even neurotypicals have their limits, and I wouldn't want to be one of them: and then, about what is 'normal,' I'm not going to elaborate" (e-mail to members of Gruppo Asperger, April 23, 2009, translated by Crocetti).

Certain themes and opinions emerge clearly from this document that we would like to briefly highlight: first and foremost there is a trust and hope that through scientific research possibilities will be found to better the lives of people with Asperger's syndrome. It is through scientific research, for instance, that the group distances itself from the DAN! method that proposes a cure capable of combating and eliminating autism. DAN! supporters have not shown interest in dialogue with the scientific community. It is in the language that DAN! supporters use that Aspies do not identify for a simple reason: *Asperger's syndrome is not a disease*. The majority of the members of Gruppo Asperger do not consider themselves sick, they feel they have problems in certain areas (that vary from person to person), as well as feeling that they have certain gifts that should be helped and valued.

The objective of the Aspies is not "to be just like everyone else," but to have their differences recognized and accepted by themselves and by those who are neurotypical. Many Aspies are proud

to be who they are and would not want to be different, even if they could. The vice-president of the group is a prime example and very clear on the subject. Therefore the war-like language of elimination, defeat, like cancer, used by the DAN! method supporters, and their promises of a cure for a state that Grupo Asperger does not consider pathological but problematic for those who live with it, obviously creates opposition.

Another point of contention in the proposed law is the use of the word epidemic when referring to an increase in diagnosis in a psychiatric syndrome with possible genetic markers. This imprecision speaks to the underlying moral implications implied in disease discourse, besides obviating a comment on the involvement of social factors in the augment of diagnosis. In the case of Asperger's syndrome, the increase of diagnoses is related to access to neuro-psychiatrists familiar with the syndrome but also with the interpretations and mutations of the diagnostic categories of the DSM IV TR and the ICD-10 that reflect the criteria of the delimitations of the syndrome (Hacking 1999).

The phenomenon of self-diagnosis indicates that some prefer being considered an Aspie, instead of being considered problematic without a specific label. Activist Martijn Dekker believes that women are under diagnosed, indicating that a particularly quiet female child will not be seen as problematic in the same manner (Drekker 2004). A female Aspie psychologist observes: “la donna compensa di più, e per questo solitamente viene diagnosticata al limite come depressa” (“Women compensate more, and because of this usually are diagnosed at most as depressed”) (L, conversation with author 1, 8 May 2010).

## AISIA and KIO

Historian Alice Domurat Dreger outlines the intensification of medical interest in defining *true sex* in the eighteenth hundreds in *Hermaphrodites and the Medical Invention of Sex* (Dreger 1998). Within the historical medical literature there is an alarmist notion that hermaphroditism was becoming epidemic. Dreger's critique highlights how heightened medical interest in the physical

manifestations of gender expanded the category of hermaphroditism to include many more deviant bodies, thereby inventing a significant increase of hermaphroditism. The eighteenth hundreds lead to the expansion of categories such as male and female *pseudo hermaphroditism* and then at the beginning of the twentieth century *Intersex* began to be used (Dreger 1998).

The term DSD (Disorders of Sex Development) was adopted as the new biomedical terminology in the consensus consortium convention in 2005 in Chicago. One of the issues embedded in changing the terminology from *Intersex* to DSD is a shift away from a gender identity politics framework towards disability politics framework, in which establishment of the normal body and manipulation of the body become the primary issues. However the continued use of *disorder* and the medicalized context has left many unsatisfied (Reis 2007). The development of these changes, and the role of American *Intersex* support groups, is well documented by Dreger and Herndon's (2009). Many authors question not only the standardization regarding gender as a social category, but also the standardization of the components of biological sex that have lead to the medicalization of the gendered body (Dalston and Park, 1981; Fausto-Sterling 1985; Dreger 1998).

ISNA (Intersex Society of North America), a pan-Intersex patient group that questioned above all the silence and secrecy surrounding *Intersex* treatment, was founded in 1993 by Cheryl Chase who had been medicalized in early childhood. Many issues surround *intersex/DSD* medicalization, including informed consent, childhood surgery, standardization of gender identity and the gendered body, medical stripping (repeat genital examination), abnormality as pathology, pre-natal testing, disability theory, among others. INSA directly contradicted the medical explanation of early childhood surgery as important for future psycho-social health. ISNA was in turn criticized by doctors, as representing only dissatisfied patients. The medical theory, inconsistent with the growing trend of follow-up research, was that a patient that 'disappeared' was a satisfied patient who had reintegrated into "normal" society.

Across the globe patient groups have formed that represented either individual syndromes or

Intersex as a medicalized category. However, even today, the discourse remains largely dominated by the English language. Italian group websites frequently post international articles that they translate to Italian, to compensate for the lack of material written in Italian. Older patients describe how crucial the Internet, often navigated in English, was in finding information about the syndrome. Many Italian doctors in the field publish in English. Recently, however, revised medical textbooks in Italian that discuss Intersex/DSD (Domini 1998, Balsamo 2005) are appearing. Sociological debate and patient voices in Italian were virtually non-existent until the formation of the patient groups. There are a handful of historical texts that address the development of “bi-sexual” legislation (Marchetti 2001) and diagnosis categories (Caffaratto 1963, Taruffi 1898).

The Italian patient groups are not pan-Intersex and do not engage directly in a gendered discourse or an anti-normalizing platform. Therefore they do not directly address the social aspects of gender stereotypes or conformity in Italian society. (Individual members, however, have varied strong opinions about the gendered axis in DSD treatment). Their first line agendas are de-stigmatization and useful (strategic) medicalization. One of the key aspects that is evidenced by AISIA (Associazione Italiana Sindrome da Insensibilità agli Androgeni) and KIO (Klinefelter Italia ONLUS) is the use of collaboration with hospitals and doctors to subvert the dominant treatment model. In directing attention towards physiological health concerns they redirect attention away from gender assignment and genital surgery.

DSD diagnosis and treatment has a history of secrecy, wherein the decision or practice not to inform patients and families of the particulars of the diagnosis and/or treatment was considered important for the psycho-social health of the individual. Whereas the founders of the AISIA group experienced this medical tradition first hand, the group is directly involved in changing this protocol of secrecy. AISIA was officially founded in Italy in 2006 and while directly representing Androgen Insensitivity Syndrome, it functions as the closest representative of a Pan-DSD group.

AISIA was started by two parents frustrated with the options and lack of information the

doctors were giving them. They brought their daughter into the hospital for a hernia, and were confronted with the alarm of the surgeons who burst into the waiting room saying, “We don't know if your child is a boy or a girl we need to do something right away!” They were insufficiently informed to make the quick decisions being pressed on them. They started searching the Internet and found the UK AIS group. They then went to London and met with doctors who taught them about dilation techniques and different care options. When they came back to Italy their doctors were incredulous and refused their attempts to find other patients in their situation. In the period from 2006 to 2010, the discourse with medical authorities has shifted policy rapidly to affirm informed consent. Unfortunately many older members repeat the refrain: “If I had only known, if I had been told”.

In 2006, an international medical conference on Intersex was held in Rome, attended by doctors from a wide range of countries, where simultaneous translation to English was provided. The newly formed AISIA (still in unofficial form) had a table with their poster presentation. Participating physician Dr. Ian Hughes presented the consensus consortium’s clinical guidelines for a new model of patient-centered care and the new DSD terminology (Hughes 2006).

The clinical model of patient-centered care model seeks to replace the optimum gender of rearing (OGR) model developed by John Money and his colleagues at John Hopkins University in the 1950s (Money 1955). The OGR focuses on fixing gender assignment through surgical intervention, reinforcing gender identity as the primary concern in Intersex disorders. The patient-centered care model seeks to address some of the controversy created through a non-informed surgery model, as well as reorienting the medical focus towards physiological issues such as cardiac health and bone density. The principles outlined in the patient centered care model are representative of the lines of conflict addressed by patient support groups:

- (1) Provide medical and surgical care when dealing with a complication that represents a real and present threat to the patient’s physical well-being.
- (2) Recognize that what is normal for one individual may not be what is normal for others; care providers should not seek to force the patient into a social norm (e.g., for phallic size or gender-typical behaviors) that may harm the patient.
- (3) Minimize the potential for the patient and family to feel ashamed, stigmatized, or overly

obsessed with genital appearance; avoid the use of stigmatizing terminology (like pseudo-hermaphroditism) and medical photography; promote openness (the opposite of shame) and positive connection with others, avoid a “parade of white coats” and repetitive genital exams, especially those involving measurements of genitalia.

(4) Delay elective surgical and hormonal treatments until the patient can actively participate in decision-making about how his or her own body will look, feel, and function; when surgery and hormone treatments are considered, health care professionals must ask themselves whether they are truly needed for the benefit of the child or are being offered to allay parental distress; mental health professionals can help assess this.

(5) Respect parents by addressing their concerns and distress empathetically, honestly, and directly; if parents need mental health care, this means helping them obtain it.

(6) Directly address the child’s psychosocial distress (if any) with the efforts of psychosocial professionals and peer support.

(7) Always tell the truth to the family and the child; answer questions promptly and honestly, which includes being open about the patient’s medical history and about clinical uncertainty where it exists. (Intersex Society of North America 2006)

These guidelines led to the creation of a parent handbook and clinical handbook. In 2009, AISIA translated and made available the Italian version of the parent handbook on their website. In the future they hope to edit the handbook to reflect an Italian context, from negotiating the public health system to information sharing. Public health can often mean the standardization of obstacles to individual care while at the same time providing free help. Many AISIA members do not get free hormonal replacement therapy because they would have to accept the stigmatizing health code of pseudo-hermaphrodite.

Parallel to the presentation of these guidelines at the 2006 convention, one of the main DSD treatment centers in Rome presented its newly formed treatment team, composed of a psychologist, a surgeon, an endocrinologist and a geneticist, highlighting a desire to follow the consensus convention guidelines. However, these half-day presentations were followed by a day and a half of presentations of new surgical techniques. Overall there seemed to be a disparity between the new clinic patient-centered model and the time devoted to surgical technique, however one cannot expect a paradigm shift to be enacted in a day.

AISIA members had been told by their Italian physicians, that early vaginoplasty and gonadectomy was the only possible therapeutic model. In response in 2009 they negotiated with a Roman research hospital and invited a London gynecologist to present a paper on dilation techniques

and other non-invasive models. This gynecologist also mentioned that it is well known and commonly ignored that the clitoris is often the key to female sexual satisfaction and should not be damaged for the sake of aesthetics. AISIA also invited a psychologist whose talk centered on the psychological damage caused by medical stigmatization and lack of information. Before these talks, the role of the psychologist in DSD treatment was restricted to gender identity evaluation.

In 2010 AISIA created a scientific committee that includes the previously mentioned psychologist, a surgeon, an endocrinologists and a pre-med patient member. AISIA now collaborates with three university medical centers in Italy that are creating a genetic database and research on hormones. One research shows higher bone density and better cardiac health in those who have not had early gonadectomy, regardless of the type of hormone replacement therapy.<sup>8</sup> This center is rapidly diluting the concentration of medical papers on surgery and gender assignment, with research on cardiac health, bone density and other hormonal health concerns. Their collaboration with AISIA has given them an authoritative voice in that their database is bigger than other Italian hospitals and has given AISIA an authoritative voice in changing treatment protocol.

AISIA's position towards early vaginoplasty and gonadectomy shifted as they have become aware of other treatment options, not initially mentioned by their doctors, but also aware of each other. In July 2010 they had their first direct policy encounter with one of the collaborating university hospitals. In this encounter in a heated moment of discussion with the head surgeon it became apparent that not only all of the group members who had had vaginoplasty suffered side-effects, but those who had not had surgical intervention had resolved in other manners without the presumed psychological trauma induced by being different. The feeling of difference and frustration plagued those who had had surgery. In four years AISIA has grown to over a hundred contacts, often accompanying each other on medical visits. The activities of the group have expanded to include

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<sup>8</sup> Another Italian university hospital has started experimental therapy with androgens, to which a handful of patients mentioned happily they had also had also experienced positive “mood” effects such as the later mentioned sex drive issue that were not the original object of the therapy.

separate parent/patient encounters, group therapy and planning sessions.

Although AISIA's participation in medical conferences has shifted their position to one of authority, their presence is generally non-confrontational, one of observing and alliance seeking. In this manner they do not criticize directly specific techniques in public, but the lack of information and options offered. As alternate techniques become known, the validity of the previous options shift in perspective. The Internet has lead them into the global framework that has lent strength to their voices, and it also helps them find each other, becoming the largest resource for DSD related issues in Italian.

*KIO.* Klinefelter Italia Onlus is one of the three DSD patient groups active in Italy. It was founded in 2004 after the first Klinefelter patient group, founded in 2002, was taken over by doctors. The founding member, Mr. X, spoke about his relief when he finally got an accurate diagnosis and description of Klinefelter's syndrome. He had first been diagnosed when after years of trying to have a child and after his wife had been examined, he insisted that he be tested for in-sterility and was found to have low testosterone production and then Klinefelter's syndrome. A second doctor told him he would not live past 40. Years later he went on hormone therapy. He talked about the changes he felt when he began testosterone therapy, more active, more energy, more libido, as if he had finally become *himself*. He seemed very happy with the masculinization of his body (less body fat ratio) and the effects of the testosterone on his personality.

However as the founder of the group continued his story, it turned out that what had sent him back to the doctor and lead to the hormone therapy was not his gender presentation but debilitating headaches that had been going on for years.

Hormone replacement therapy in conventional DSD treatment was prescribed for gender presentation and homosexuality. Hormones and Chromosomes have become the 20th century emblem of biological gender (Oudshorn 1994; Roberts 2007). Even though homosexuality is no longer considered a pathology in and of itself, it is still often considered or treated as a symptom in Intersex

syndromes linked to hormone imbalances. This is one of the myriad ambiguities around what exactly is being medicalized with DSD: Is it social expectation of gender related issues such as physical gender presentation, gendered behavior and even reproductive issues? Or is it physiological health complaints such as headaches and osteoporosis? This ambiguity within endocrinology runs the course of the research. In practical terms many Klinefelter patients are given hormone therapy to increase their sex drive, which may have correlating positive effects for headaches, there is little study on other elements (Cameron in Dreger 1999: 94-96). Doctors will hardly ever recommend hormone therapy specifically to increase the sex drive of a female patient.

KIO mobilized an information campaign in response to the highly publicized pre-natal testing and abortion case in Naples in 2008 in which Klinefelter's syndrome was described as a “grave genetic illness.” They focused on people’s actual experiences with Klinefelter’s syndrome, and new statistics directly informed by the increase in pre-natal testing, indicating a Klinefelter's frequency of 1 in 700.

The support groups’ experiences reflect the relation of knowledge to power, reflecting Foucault’s discourse on medical control and interest in body norms. Earlier we mentioned the shift from an Intersex identity politics paradigm to a DSD disability politics paradigm. As long as the medical protocol continues to focus on the gender identity aspects of DSD, a critical reminder of gender theory is important. The negotiation of body and behavioral norms in DSD is often linked to the societal stigma surrounding ambiguous gender roles. However, disability theory applied to DSD has created the option to directly address the medical pathways of establishing and enforcing embodied and behavioral normalization. The hope is to put further light on the function and definition of pathology, statistical norms, symptomology and the medical fix.

## The Art of difference

International Intersex activist Emi Koyama gives a clear synthesis of the relationship of DSD medical categories to disability theory, focusing her debate on normalization of the body instead of

gendered politics.

While most people understand the word “disability” to refer to a list of physical characteristics that cause difficulties or inconveniences to people who possess them or those around them, from that point of view one could argue that intersex has nothing to do with disability because it does not cause any difficulties or inconveniences on its own. But to a disability theorist, disability is not simply a characteristic of one's body, but the product of social institutions that divide human bodies into normal and abnormal, privileging certain bodies over others.

In this view, the physical condition that necessitates the use of a wheelchair in order to move about is not itself a disability; social and architectural structures that deprives a wheelchair user of full participation in the society is what disables her. Similarly, intersex activist Esther Morris's observation that “not having a vagina was not my problem; having to get one was,” can be paraphrased to say: not having a vagina was not a disability; the social expectation that she needed to get one in order to live happy and productive life marked her body disabled. (Koyama 2006)

The discourse embedded in the social expectations of bodily and social performance is tied to the relation to the statistical norm as a defining factor in pathology (Canguilhem 1989). Historical research indicates the expansion and contraction of pathological categories such as hermaphroditism and autism.

In this example, Grinker references the dynamics of expansion and contraction of physical categories:

The effect of the broadening criteria on prevalence rates can be observed in statistics from California, where the number of people who received services between 1987 and 1998 under the category of autism rose by 273 percent. Gernsbacher and colleagues, in a 2005 journal article, used an analogy to show how such an increase could happen in the absence of a true increase in incidence. They asked readers to suppose they had asked how many of the men who lived in McClellan County, Texas, were “tall” at two different point in time – the mid-1980s and the mid-1990s, using two different definition of tall. Suppose also that in the mid-1980s, “tall” was defined as six feet, two and a half inches, but that in the mid-1990s, the criterion was loosened a little, to six feet. There would have been 2,778 tall men in the earlier group, but 10,360 men in the later group, reflecting a 273 percent increase (the same size increase, incidentally, as the change in autism rates in California from the mid-1980s to the mid-1990s). (Grinker 2007:158-159)

This example is obviously not indicating an actual increase in height in Texas. In the same manner, it is unclear whether recent history has actually seen an increase in the phenomenon of autism or DSD. In some cases the criteria defining the category has changed, in others there is increased scientific and social interests, making the category more visible. For example, the diagnostic symptomology for Asperger's syndrome is based on a percentage scale, creating a fuzzy and elastic category. In this

light, the problem isn't understanding if a person is, for example, too sensitive to have a highly developed interpersonal life, but when and at what point on the spectrum one moves from a desirable situation to an acceptable situation to an abnormal unacceptable situation.

In other words, how does one work with categories of pathology in which the defining line is a graduated difference? The actions of the patient groups indicate they believe the answer to lie in communication, negotiation, and cleaning the medical category of social stigma. Diagnosis comes to canonize a subjective moment. In the case of Asperger's syndrome the metaphor of the graduated spectrum is quintessential, in which each individual may manifest combinations of each extreme of the spectrum. In DSD the surgical manipulation of infant genitals has been based on standards of size and shape that ignore the vast variety of the human body. The development of DSD treatment has led away from sex assignment based solely on genital size. Yet treatment still references standardization of the gendered body, as seen in endocrinological therapy. Graduated difference in pathology proposes two issues within medicalization, 1) from the clinical standpoint, individual attention is required as to what subjective problem said difference causes the patient, and 2) from the patient's standpoint, the negotiation of the advantages and problems proposed by being labeled with the diagnosis (free therapies, access to jobs etc).

The normal has not always had the possibility to dialogue at hand's length with that which is considered abnormal. Many figures throughout the centuries have analyzed the concept of normality, often suggesting delimitations. During his lessons at the Collège de France, particularly in '74 and '75, Foucault investigated the nature of the concept of abnormality (Foucault 2000), much as his Professor Georges Canguilhem had investigated the normal and the pathological (Canguilhem 1989), looking to establish to what measure it could be defined as culturally constructed. Foucault underlines the role of bio-power in its capacity to codify life experiences and its relationship with structures of power. He references the case of a hermaphrodite in the eighteenth century that risked the death penalty because their own body represented a betrayal of the limits of sex. The hermaphrodite body

in this case confounded legal status by betraying aspects of both sexes and thereby social roles.

Bio-power acts not merely through explicit and coercive laws, but through dynamics incorporated in the social fabric of society under the form of implicit behavioral norms. In this analysis Foucault also considers the so-called human monster, capable in its mere presence, of symbolically calling into question societal structures. It is in this vein that Mary Douglas elaborates societal rules as seeking to cleanse the society of difference and therefore monsters (Douglas 2002).

In situations where the individual pathological body is made to correspond metaphorically to a weakness or pathology in the social body, the cure and care of that body takes on the role of eliminating the undesirable from the society as well. This metaphorical relationship opens the door to the intellectual premise in which social differences, corresponding to established limits, must be considered pathological and therefore must be medicalized (Szasz 1961, Furedi 2004). It is easy to extrapolate from this position the complicated nature of certain contemporary and historical medical philosophies that mix discussions concerning pathology with morality and quality of life. De Carolis states, in other words, contemporary medicine betrays an increasing tendency to “extend itself to the ethical arena: that is the arena of behavior and decisions, in which rule the more general distinction between that which is “better” or “worse” in their absolute sense” (De Carolis 2004: 175, translated by author 2).

The medicalization of behaviors or bodies is the subject of many disability theorists. Judy Singer discusses *neurodiversity* in, *Why can't you be normal for once in your life?* (Singer 1997), which frames the problems in terms of adapting to the environment. The concept of normality therefore emerges as relative to a given context, not as a natural state. Neurodiversity pulls on many different movements within Disability politics, such as the Deaf movement, that constructs itself as an identity category. Neurodiverse individuals see themselves as different from neurotypicals.

Lennard Davis addresses the relationship of morality to physical and emotional well-being in the history of eugenics, highlighting the desire to breed blind people out of the population, not because

of their hardship in life but because of an implied moral degradation in the physical disability (Lennard 1997). Ellen K. Feder relates Foucault's discussion of medical power and normalization to Davis's historical analysis of the nineteenth century "model man" (Feder 2009). We fear the power of normalization because of its potential power to eradicate, but also to judge. Davis reiterates the need for caution in seeking genetic causes for disabilities, not only because of the historical misuse of eugenic practices, but because disability and difference itself is socially framed.

And then there was genetics

Within the disabilities politics framework, and not only, it has become increasingly important to think about genetic technology (Shakespeare 2005), what it does performatively, and what it implies for personal identity. Both DSD and autism are tenuously associated with genetic markers. At the current moment, the association of genetic markers with a pathological category has primarily diagnostic relevance (Lindee 2005). Although the public understanding of genetics is still linked to the mendelian model (one gene: one trait, understood as the gene for X), research points to the complex interaction of development, and intercellular interaction in gene expression (Jablonka 2005).

This raises a red flag as to what genetic testing does in medical practice vis a vis the syndromes discussed here. As in the 2008 Klinefelter case in Naples, one can see the direct correlation between genetic testing and the eradication of difference. The communication of accurate diagnostic information and risk calculation is often missing. In a London research, a radical difference was found in Klinefelter diagnosis pregnancy termination based on whether a gynecologist or a genetic counselor communicated the chromosome test results (Hall et Al. 2001). These results have been repeated in several other countries (Yon-Ju et Al. 2002, Mezei 2004). Authors explain their findings by proposing that a genetic counselor is more likely to explain genetic indicators as representing a varied spectrum of development as well as having more updated information about genetically linked

syndromes. The Klinefelter's group promotes genetic research *because* they feel it will show how common and diverse the syndrome is.

Currently pre-natal testing is for the most part chromosomal, thereby detecting syndromes such as Klinefelter's and Down's but not AIS or Asperger's. Thereby the fear of eugenic elimination practices can be limited to chromosomal prenatal diagnosis and not molecular genetic testing as of yet. Margaret Lock refers to the increase of genetic testing as the new divining (Lock 2005), a new diagnostic tool that indicate probabilities, much like the ancient Greek oracles. Pre-natal testing reflects not only our expectations of what technology, or bio-medicalization, should be able to do for us (Ettore 2000), but also the expectation that we reject of perceived imperfection (Rapp 1999). Post-natal testing instead can represent a bio-technical explanation of identity and difference. Nikolas Rose discusses the nuance in genetic diagnosis of being "potentially unwell" (Rose 2004).

In a recent case at an Italian university hospital DSD care center, molecular testing revealed a 5 alpha reductase genetic marker, changing their original PAIS diagnosis. In the western world 5alpha reductase usually given a male gender assignment and PAIS a female. The parents were counseled to raise the child as a boy with a micro-phallus and postpone surgical intervention. The shift to medicalize the parents dis-ease with a non-standard body through therapy in this case seems to have been instigated by a faith in the implications of genetic markers. The belief in western biomedicine that 5alpha reductase indicates a male gender identity directly shifted care protocol in two key manners. The social acceptance of a boy child with a micro-phallus, and the advice to postpone intervention until the patient is self-determining, diving deeper into the body to a molecular genetic marker such as 5 alpha reductase.

Molecular genetic technology shapes diagnostic practice at the current state of the technology. How that diagnosis is then used is the key to patient satisfaction, as we can see in the Asperger's group's criticism of the unidirectional DAN! therapy model. Patient satisfaction in the end is driven by what patients themselves see as problems to be resolved. The groups that we work with all support

genetic research on a certain level, hoping that it can be another tool of useful medicalization, as opposed to stigmatization and normalization.

Vernon Rosario hypothesizes that the complexity of genetic expression promoted by molecular research will lead to a equally complex model of sex and gender that he calls quantum sex (Rosario 2009). However, historian Garland Allen references his own difficulty in teaching a non-mechanistic model of genetics (Garland 2002). The professional use of genetic counselors may help in the diffusion of a non-deterministic model.

## Conclusion

In this paper we have represented syndromes with very diverse natures, autism (Asperger) and DSD. In comparing our groups we have continuously found the commonality of the struggle with the *legislative frame* of biomedicine. We find ourselves before a set of practices, called medicine, that seeks to create boundaries for the normal, and thereby healthy, by using statistical measurements of the body, its functions, behavior, gender, IQ (Gardner 1993) and social interaction. The role of the medical sciences in these cases is blurred between the Hippocratic oath to alleviate suffering and the delimitation of a symbolic territory of pathology in which one requires intervention. It often seems that there are large categorical leaps between a perceived difference, a syndrome and a disease; this is evidenced by the confusion made in the use of these terms.

The patient groups work on a practical level creating protected spaces in which they can share experiences and create a continuing dialogue. Through the explicit and underground discussions with medical practitioners and experts, they contribute to the subtle changes in practice and definition that reflect their point of view. The positions of the groups are often much more elastic and individually oriented compared to the official diagnosis. The group positions relate directly to individual experiences that reflect the problems of everyday life.

One is able to see the direct effects of the shift of treatment, won through the work of the

young groups. AISIA and KIO have gained a hard won position of authority within the national discourse, and are now invited to medical conventions. Their activism addresses the way that diagnosis is communicated and when body-changing therapies will be performed.

The Gruppo Asperger also embraces the diagnosis while insisting on the right to negotiate or undertake therapy. The social groups they form prove their social abilities provided the context. They have had to directly confront the legislative aspects of psychology in their confrontation with the legal proposal that promoted only one type of therapy.

The groups we have worked with are not interested in rejecting the diagnosis, but rather the stigma and invasive therapy models that has been often exacerbated by the same diagnosis. Within the groups the diagnosis has helped create community and alleviate the suffering of feeling of monstrosity. There is not a totalizing attitude that medicalization is negative, rather that the medicalization needs to be redirected to alleviate the complaints of the diagnosed, not the complaints of a normalizing society.

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