Women from another planet? Feminism and AC awareness

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Introduction

My interest in this topic is twofold: from the perspective of the disability movement and culture and from a book project about women on the autistic spectrum that I have been involved with.

Recognizing my place on the autistic spectrum, and intense involvement with Autism Network International, got me fixated on the notions of community and culture among autistic people and among disabled people in general. Surfing the Internet for disability culture, I was surprised to realize that many of the writings about disability culture were by female authors. Moreover, most of the authors, men and women alike, drew parallels between feminism-related issues and disability awareness and advocacy.

Another source of inspiration was working on a book called "Women From Another Planet? Our Lives in the Universe of Autism", an anthology initiated and edited by Jean Kearns Miller. Many of the contributors participated in a discussion list where we brainstormed about the issues we wanted to write about and the message we wanted to convey. An important issue in those discussions was the interplay between the roles of women in society - both from a traditional and from a feminist point of view - and our characteristics as AC women. These discussions, and the name of our book, which drew on a well-known book about gender differences, motivated me to learn about the essence of womanhood, at least as it is known in NT women. I learned that, in spite of the radical changes that the feminism movement was trying to make regarding gender roles in society, the characteristics of women in interpersonal interactions remain inherent to their NT female psyche and are markedly different from what I know about myself and about many AC women. While women with other disabilities are excluded from the mainstream feminist movement due to political and accessibility reasons, the obstacle for inclusion of AC women in this "sisterhood" is much more profound and hard to overcome.

AC awareness as a cultural minority issue

Parallels between race, feminism and disability

Issues of race, feminism and disability are all closely related to values and beliefs. It is now politically inappropriate to discuss racial characteristics of people and nations. Less than a century ago, however, racial differences were believed to constitute scientific grounds for discrimination and physical elimination of certain ethnic groups. Cultural and behavioral prejudices (disguised as scientific truths) claimed a basis in genetic properties. Nazi propaganda used pseudo-scientific Darwinist ideas to portray black people as inferior to white people, and Jewish people as a threat to civilization. In less extreme and much more abundant cases, beliefs about the superiority of western culture were used to justify imperialism and oppression of non-western ethnic groups. The dominant culture - the western culture in this case, owned by white people - was taken to be the standard, versus which all other people and cultures were to be measured. Any difference from the dominant culture was portrayed as a deviance, and people who did not belong to the "right" race were "The Other" - the inferior or the monstrous. Early anthropologists always examined "the odd" - "primitive" cultures. White man was the active subject, the observer, while non-western cultures were the observed, and non-white people were the passive objects of observation. White people, and western culture, were not examined then by anthropologists, as they were taken as the obvious, the unquestionable.

In our age of relativism and multi-cultural diversity, ethnic origin and culture are viewed as different, not as inferior. Economic, political and social status of minorities, such as black people in America and Muslims in Europe, are no longer discussed in "neutral" terms of science, but are now in the realm of beliefs and justice. Although many people still fear "the Other" and may hold racist views, it is now harder to express these views in public, and many states have established laws to prevent these views from gaining political power.

Similar to racial differences, the inferiority of women was discussed in the late 19th century in medical terms of pathology. Menstruation was described by physicians as a never-healing wound. The female body was viewed as a mutilated masculine body: a castrated, penis-less body. Freud based his psychological theory of women on this assumption. The description of being a woman was reduced to pure physical existence. An important feminine virtue was, and still is, the ideal of beauty: a woman is judged by what she looks like, while a man is judged by what he does. Women are still denied access to certain occupations for the sole reason of being females. Physical differences between males and females were exaggerated,

using clothes and makeup, to distance males from "the Other" and maintain men's dominance. Any gender ambiguity was, and still is, a threat to gender hierarchy, and therefore is eliminated relentlessly. Inter-sexed babies are treated by surgical procedures "for their own good". Here again, the deviance from standard sex classification is discussed in medical terms of pathology.

Feminism is telling us that biology is not destiny. It works to transform the portrayal of women from purely physical creatures to whole people, a combination of flesh and spirit. While sex differences are *neutral*, gender is a social construct, meanings and cultural symbols *imposed upon* physical reality. Feminist scholars and writers analyze the ways in which the dominant culture, male-oriented in this case, maintains the status of women as "Other", a passive object of observation. Women's movements are trying to change the role of women in society, from passive to active, from second-class citizens to full participants in society. The role of women in society is now discussed in social terms of oppression and justice, rather than in the supposedly "neutral" terms of biology and psychiatry. There are still people who hold sexist views, but many countries are setting up laws to prevent sexual harassment, domestic violence and discrimination on the basis of sex. The disability movement is now trying to change the image of disabled people and their role in society, similar to the way the women's movement has been doing for women. Disabled people are still viewed as inferior, inherently inept and dependent, limited by their biological and mental makeup. It seems obvious to many non-disabled people that a blind woman can't clean a house, or that someone who can't talk is not intelligent. A common belief is that disabled people can never be happy. Disabled people are denied access not only to employment, but also to proper education (needed to develop vocational skills), based on the assumption that having a disability means inability to work. Behaviorist treatment methods relate to autistic children as purely-physical beings, disregarding the internal reasons underlying odd behaviors. Uta Frith even argued that autistic people have no self-awareness. Disability is defined by the deficits of the individual, as measured using scientific or medical terms compared to an unquestionable ideal of normalcy. Defining what disability is, setting personal and societal goals to deal with it, and developing services to achieve these goals are all assigned to health professionals - the ones who are believed competent to apply "neutral", "objective" judgment.

Similar to a beautiful woman who is the target of a man's desire but is never understood, disabled people are the target of the normal stare. In the past, disabled people were used in "freak shows". Today, some autism conferences bring a "token autistic" to give a talk, often

titled "My personal experience with autism". Common to all of these situations is the use of a person as a spectacle.

As much as issues of race and gender are a matter of values and beliefs, disability is also a matter of stigma and prejudice. Similar to feminist authors, disability scholars analyze the ways in which the dominant culture, able-oriented in this case, maintains the status of disabled people as "Other", a passive object of observation and treatment. Murphy writes: "Just as Women's studies is not the study of women's reproductive organs, Disability Studies is not the study of medical/psychological/legal definitions of disability. Both subscribe to standpoint theory. That is, you cannot understand my experience unless you look at it from my point of view". The social model of disability distinguishes between impairment, which is how the disabled person differs from the norm, and disability, which is how this difference limits the disabled person's life. The biomedical model focuses on the "disordered" individual, and seeks to improve his or her life by a personal change towards normalcy. In contrast, the social model of disability looks at the supports that the community offers to its members and seeks to augment them by including supports which would enable disabled people to become active participants. The disability movement fights to move the discussion on disability issues from the medical field to the realm of social justice.

Similar to feminist women, who no longer feel inferior to men, disabled people who are self-aware are no longer ashamed to identify as Disabled. Disability culture, emerging from the experiences of disabled people coming together and speaking up, is seeking to be recognized as a legitimate alternative to the mainstream culture. Crip culture is emerging from the different life experience of physically-disabled people, which spread far beyond practical, daily activities. Vasey writes: "Being Disabled weaves itself into the fabric of life in all its aspects and very importantly it is not an entirely negative experience. For example, in the course of being helped in the loo I have made any number of friends, in fact I often find the bathroom is an ideal place to get to know people, or cement a friendship". The Deaf culture is built around sign language as a different communication means. Autistic culture expresses the special ways that autistic people perceive the physical, emotional and social world. In spite of these advances, the situation of disability is way behind that of race or feminism. While feminist ideas are widespread, the disability movement and its ideas are not even known among many disabled people.

The importance of an insider's view

An insider's view is important for understanding the experience of living with a disability. In fact, autobiographies of and media interviews with disabled people generate interest in the public; they are a kind of curiosity, telling "what it is like" to be disabled. This is especially true for autistic people, who are considered "locked in their own world". However, this kind of interest only reinforces the image of the freak, the Other. I find that the more important aspect of self-expressions of disabled people is related to values and desires. This aspect reveals an even more profound difference between the assumptions of non-disabled people *about* disabled people and the actual self-perception *of* disabled people. In this area, there is less interest, and even less willingness to accept the disability point of view.

LaSpina writes: "When they ask me to explain what I mean when I say 'I don't want to be cured', I always answer 'The same thing I mean when I say I don't want a penis'. And the immediate response is: 'Oh it's not the same thing! You really are disabled!' Yes, I really am Disabled and I have no desire to be non-Disabled. Just like I really am a woman and I have no desire to be a man." LaSpina does not use person-first language. Many autistic people prefer to use Autistic as an adjective and a noun to describe themselves, rather that to use person-first language. Just like you won't call me a person with womanhood, I don't want to be called a person with Asperger Syndrome. I am an Aspie.

In addition to fighting for civil rights for women, feminism has worked to transform the image of women in the dominant culture, and moreover - in the eyes of women themselves. Instead of an inept, dependent person, the "new woman" promoted by feminism is strong and independent. Feminist women are *redefining womanhood*, demanding control over their bodies and their lives. Similarly, disabled people are claiming disability: No longer ashamed to be who they are, disabled people are coming together and forging their identity, rather than internalizing the pejorative description of professionals and of the dominant, able-oriented culture.

An emergent field of gender studies is revisiting history, to examine it from a gender POV and uncover the contribution of woman throughout history. As long as historiography was solely in the hands of men, the role of women in history, as well as entire areas which are of interest specifically to women, were overlooked. One of the results of this process was the scarcity of positive role models for women and girls. Nowadays, girls can dream of being not only a beauty icon, but a scientist like Marie Curie or a prime-minister like Indira Gandhi and Golda Meir. Disabled youth have very few disabled role models to look up to. Ferri and

Gregg write that "the few images depicted in literature, film, photography, and even in the Bible, used disability as a metaphor for broader themes, like death, tragedy, struggle and vulnerability. The woman with a disability is rarely the heroine and most often the victim". The disability movement is developing its own heroes - leaders who fight for disability rights and develop new community living services, as well as scholars and artists expressing the disability experience. One of the goals of Autism Network International is to connect autistic children and youth with autistic adults who are self-aware and are not ashamed to identify as autistic.

Gender scholars are questioning the existing social order, and putting forth an alternative society, based on more women-friendly principles. An example from management is a system built on cooperation rather than on competition. The emergence of "the new woman", liberating women from futility and dependence, is accompanied by a "new man" image, which is liberated from the demands placed upon the "macho". Feminist men celebrate the new freedom to express their feelings and to be more meaningfully involved in their children's lives. Similarly, the portrayal of disability as a legitimate way of being, and rejecting the illusion of normalcy and perfection, can help non-disabled people to accept themselves for who they are. Some of the needs of autistic people for clarity and their observations on the illusion of instinctive understanding among NT people may benefit non-autistic people too. If people did not assume that others could read their intentions, but instead expressed themselves explicitly, a lot of misunderstanding would be prevented. Thus, the new insider's angle brought forth by minorities like women and disabled people may improve society at large.

Respecting differences

Social movements related to ethnicity, gender or disability started out with a goal of integration into society. One way of trying to be accepted into society is assimilation. People of various ethnic origins started to dress in European clothes and adopted Western habits. Women wanting to succeed in business wear business suits and act according to men's rules, sometimes giving up marriage and children. Disabled people try to pass for normal, often at the expense of their health and mental well-being. As with the Superwoman, who manages career and family life (as well as keeping in shape), society is willing to accept the "supercrip", the disabled person who has "made it", has "overcome disability". Examples are, the Deaf person who reads lips and talks, the Polio survivor who can manage the stairs, using crutches instead of a wheelchair, and the autistic person who learned to maintain eye-contac,

and succeeds in appearing indistinguishable from normal peers. However, acceptance that depends on ignoring differences is insulting. What is the meaning of acceptance, if the condition is that one has to disappear first and re-appear as someone else?

Moreover, ignoring differences may be dangerous. Gender and disability are not only a social construct, they *do have biological bases*, implying different needs. For example, the female body responds differently to some medicines, so testing of new medicines should include examination of sex differences. Likewise, disabled people have special needs that should be recognized. Many autistic people need consistency and structure in their lives. Ignoring this need may lead to exhaustion, disorientation and even outbursts and deterioration of mental health.

As disability and femaleness are minorities in the social sense, a disabled woman faces double discrimination: statistics show that the options available to disabled women in education, employment and health care are more limited than those available to both non-disabled women and disabled men. In addition, disabled women are concerned with issues that are usually of less interest to disabled men, like reproductive rights and parenting.

While issues of employment and vocational rehabilitation are widely recognized by professionals, there is very little support in the area of child rearing. On the other hand, the common child care services are often inaccessible for disabled women. Therefore, both researchers and service-providers should be aware of the special needs of disabled women. Both disability and gender are components of self-perception, or *identity*. Disability scholars write that the presence of a disability in a person often eclipses other aspects of identity. However, race, social class, gender and sex orientation may result in a different disability experience. All these aspects together, rather than only the dimension of disability, make up a person's identity.

Likewise, the presence of a disability changes the way a woman perceives her gender identity. Rather than internalizing the image of a disabled woman as devoid of sex and of gender role, feminist disabled women are claiming both their disability and womanhood. Ferri and Gregg write: "Women with disabilities must forge a gender identity, since one will not necessarily be imposed". If gender is a social construct, then autistic people, who are less aware of social norms, are less likely to develop a typical gender identity. Autistic girls may not envisage themselves becoming wives and mothers when they grow up. If social constructs are made of symbols and representations, then autistic concreteness may lead to a less generalized, and more personal gender identity. Therefore, autism may redefine womanhood in a unique way.

Political activism, community and self-awareness

Both The disability movement and the women's movement fight for social and legal rights. For many women and disabled people, the movement serves not only as a framework for advocacy, but also as a means of personal development. People finding themselves together in the same situation often develop some kind of a relationship. They may remain just acquaintances, or become very close friends. Sharing similar experiences - of womanhood or of disability - makes this relationship more meaningful, and assists in forging a self-image that draws on the values and culture of the movement, rather than on the dominant, oppressing culture.

Faherty, a TEACCH staff member who started a support group for autistic women, recalls: "I remember the strong comradery and support of 'women consciousness-raising groups' that sprouted up on college campuses and in living rooms in the 60's and 70's" Together we explored and defined what 'being a woman' was about, in the company of other young women searching for self-awareness". LaSpina writes: "We try to find ourselves in our sisters, to see other women as reflections of ourselves".

For autistic people, mere proximity does not automatically mean developing any kind of relationship. Some autistic people may be active for years with an organization related to their intense interests and still know very little about the other people in their group. Even autistic people who are very active with disability-rights organizations often find it hard to follow the social protocol of the group. Some are simply not interested in making friends there. I came here to promote ideas, not to make friends, right? Meyerding writes: "I can (and often do) feel solidarity with women in relation to political, social and economic institutions and the sexist bias they impart to women's lives. My intellect makes me a feminist. But my gut, my feelings, my self-awareness remain stubbornly un-gendered - at least in the terms of the culture that surrounds me... I spent 20 years on the project of being an ordinary lesbian " and then I gave up. ... I felt as distant (and different) from my sisters as I had been before the sisterhood began."

Still, recognizing and accepting feminist and disability-pride principles may be of great importance to autistic people. Claiming our disability - our AC-ness - means to be aware of our needs, and to take care of ourselves. It means that each one of us can participate in the ongoing process of redefining autism. For people whose autism is visible, it means to resist the negative stigma and to view themselves as different, not inferior. For people whose autism is invisible, it means to resist the enormous pressure to assimilate. For an individual belonging

to a cultural minority, keeping personal habits shared in this culture may benefit not only through the well-being associated with the habit, but may also serve as a reminder of this culture and so enhance a sense of belonging. I have experienced this sense of belonging, sometimes as helpful as a life-line, even in times when connection with other AC's was scarce.

Women from another planet?

Women's roles in traditional society and in the era of feminism

Feminist movements have fought to change women's role in society. However, disabled women are described by disabled feminist scholars as role-less. A physically disabled woman is seen as unfit to be a homemaker and a mother. How can a physically disabled woman walk, carry a baby, cook or clean the house? Disabled women are also viewed as asexual, and are thus not likely to get married. While feminists are condemning the portrayal of women as sex objects, disabled women are fighting to have their sexuality recognized. In contrast, mentallydisabled women make the ultimate sex object: they have a normal female body but lack the social or moral judgment, and therefore are seen as needing to be controlled to prevent access to sex. Retarded women are treated like eternal children and are not allowed to raise children. Therefore, while non-disabled feminists are trying to resist the traditional roles expected of them, disabled women are fighting to gain access to these roles in the first place. The relevance of the feminist image of womanhood to disabled women is even more problematic. Disability is identified with the traditional image of womanhood: a weak body and an underdeveloped mind, which make up a dependent, child-like person. Disabled women may fail to take on the role of the heroine: the woman who succeeds in traditionally masculine areas such as politics, business or academy. A disabled woman may stay in a bad marriage because she may not be able to imagine herself surviving on her own. While feminists are claiming their body and demanding the right for abortion, disabled women oppose selective abortion of fetuses that may develop a disability. While feminists are taking the active role in sexuality, they still view disabled women as sex-less, as some disabled lesbians report. Women on the autism spectrum may sometimes seem to play women roles - traditional or feminist - but in a different way, and for different reasons. An autistic woman may choose to be a stay at home mother, because she may not be able to cope with the social demands of a workplace. While typical stay-at-home mothers have a circle of friends, some of them stay at home mothers like her, an autistic stay at home mother would be literally that: she would keep to herself and her children. Many autistic women view themselves as sexual beings, but they

may choose celibacy to avoid sensory overload or the complexity of relationships. Some autistic people - men and women - are truly asexual but still may develop a close relationship with a partner of the same or the opposite sex. Some autistic women choose not to have children, not because of career considerations but because of sensory sensitivities. All the above examples apply to women whose autism is invisible. Women with a more conspicuous autism would be talked out of marrying and having children. Being a wife and a mother requires empathy, which autistic women are not expected to have.

Some autistic women may fit in the new feminist image, acquiring academic education or developing a career. However, while part of the motives of NT women for doing so are a chance to meet a potential husband, a better social status or economic advantages, autistic women may do so as a means of pursuing their special interests.

The essence of (NT) womanhood

Both traditional female roles and the feminist sisterhood stem from basic feminine emotional and interpersonal qualities. NT women automatically attach emotional contents to interpersonal relationship aspects of every situation. For them, feelings are a vehicle both to analyze situations and to connect to others. NT men, in contrast, may focus on practical aspects of the same situation, trying to resolve the underlying (non-personal) problem. Male communication is more direct and facts-related, while female communication is more indirect and relations-oriented. Men place more weight on the contents of communication, while women care about sub-text, tone of voice and body language. Women communicate for the sake of communication - as a means to establish relationships. Men communicate in order to transmit a message.

Men are more individualist and will show respect by maintaining boundaries. Women rely more on cooperation and will show that they care by sharing their concerns and encouraging others to share theirs. Women's friendships are more persistent, and are based on intimacy, sharing of feelings, and mutual support. Men's friendships are more fragmented, and are centered on shared activities or mutual material favors.

The generalizations presented here are taken from two books I used to learn about NT women. "You Just Don't Understand" by Debora Tannen, a social linguist, describes the difference in communication style between men and women. "Men are from Mars, Women are from Venus" by John Gray, an expert in interpersonal relationships, describes the difference in styles between men and women. Both books relate to these differences as cultural ones, without making moral judgment. Both books do not try to determine which

aspects may be attributed to biology and which stem from education and from societal expectations; they just describe observations. I take the popularity of these books as evidence that their portrayal of gender differences makes sense to many NT people. As an outsider I can't tell, based on my own experience or what I know about many other autistic men and women (and other genders!), whether these descriptions are true. In each and every one of the descriptions above, I don't fit with the female side. Although a few of the masculine reactions make sense to me, I don't really fit with the description of the NT man either. Many autistic people describe themselves as alien, not belonging to Planet Earth. Autistic women are neither from Venus (like NT women), nor from Mars (like NT men). We must be from another planet...

The "extreme male" theory of autism?

The link between autism and gender is obvious from the markedly bigger rates of autism in males versus females. Adding to that the similarity between characteristics of manhood and autism may lead to the conclusion that autism is caused by the same factors which shape the male personality.

The possible link between sex hormones and autism is irrelevant to autistic self-awareness and will not be addressed here. I will just point out that it would be hard to test this hypothesis, as long as there is doubt about the diagnosis of females. Attwood, Ratey, Faherty and others comment that females may be under-diagnosed, especially on the higher-functioning end. Part of the reasons for under-diagnosis in women may be related to gender stereotypes. For example, high-functioning autism is often identified with fascination with math and with computers, which are traditionally masculine fields. However, girls and women, who might be drawn to math, computers and exact sciences in general, are often discouraged by family and teachers, while boys and men are encouraged to excel in these fields, based on gender stereotypes.

Researchers addressing the issue of autism and gender should be extremely cautious about interpreting the data. External behaviors that seem to be similar between NT men and autistics (men and women alike) may result from different internal mechanisms. For example, the "Martian" need to withdraw into a cave looks very similar to the autistic need to take time off. However, for NT men, the reason is a need to work out problematic issues alone, to keep autonomy and a sense of personal achievement. For autistics, males and females alike, the reason is the need to shut down from sensory or communicational overload. Looking at various examples of differences between NT men and autistic people, the quality common to

all of them is *value judgment*: The motive of NT men is related to values and *self-image*, while the mechanism in autistic people is more "neutral" and related to more essential brain processes.

In addition, autistic men, like autistic women, may be less affected by gender stereotypes than NT men. For example, autistic men may be less competitive then NT men. Autistic boys may tend to express feelings more than NT boys. This sounds surprising, as autism in general is characterized by flat affect. However, in times of distress, autistic boys may melt-down by crying or hiding, which is in contrast with the male stereotype. Autistic men may display other feminine properties, like dependence and passivity.

Finally, the higher abundance of gayness and asexuality in autistic people in comparison to their abundance in the general population is important in understanding the relation between sex and autism.

Conclusion

Gender and disability are two components of identity that should be considered in both the disability context and the gender context: In the feminist movement, the presence of disability modifies the feminine experience. In the disability movement, the issues of relevance to disabled women should be included in the agenda.

Autistic women may have in common more with autistic men than with non-autistic women. Still, the experience of autistic women is different from the experience of autistic men, because societal expectations are influenced by gender stereotypes.

Women on the autism spectrum may find it hard to identify with non-autistic women and to participate in the feminist sisterhood. However, feminist ideas and advocacy strategies may benefit autistic people of all genders.

References

Baker, A. (2002). *The invisible end of the spectrum: Shadows, residues, 'BAP', and the female Aspergers experience*. Paper presented to Inaugural World Autism Congress "Unity through Diversity", Melbourne, Australia November 2002, http://www.autismcongress.com

Faherty, Catherine. *Asperger's Syndrome in Women: A different Set of Challenges*? Autism Today, http://www.autismtoday.com/articles/Aspergers_in_Women.htm

Ferri, Beth and Gregg, Noel: *Women with disamilities: Missing voices*. Women's Studies International Forum **21**, 429-439, 1998.

Garland-Thomson, Rosemarie. *Reshaping, Re-thinking, Re-defining: Feminist Disability Studies*, http://www.centerwomenpolicy.org/report.cfm?ReportID=80

Gray, John. Men are from Mars, Women are from Venus. 1992, HarperCollins.

LaSpina, N. (1998) *Disabled Woman: The Forging of a Proud Identity*. http://www.disabilityculture.org

Meyerding, Jane. *Growing up Genderless*. In: *Women From Another Planet? Our Lives in the Universe of Autism*, ed. Jean Kearns Miller, 2003, 1st Books Library.

Murphy, Patricia. *Why the Rehabilitation Profession Needs Disability Studies*. http://www.disabilitystudies.com/Murphy2.htm

Traustadottir, Rannveig. *Gender Patterns in Friendships*, Center on Human Policies, http://soeweb.syr.edu/thechp/genpat.htm

Traustadottir, Rannveig. *Women and Disability: The Double Discrimination*. In: http://soeweb.syr.edu/thechp/gendis.htm

Vasey, S. (1989). *Disability Culture: It's a Way of Life*. In: http://www.leeds.ac.uk/disability-studies/archiveuk/archframe.htm

Further reading

Morris, Jenny. *Tyrannies of perfection*. http://www.newint.org/issue233/tyrannies.htm Wolff, Sula. *Loners: The life path of unusual children*; Routledge: London and New York, 1995.

Baker, A., Smith, C. & Stone, H. (2000). Life and community on the spectrum: Insiders' insights into autistic spectrum differences. In Proceedings of the Next Step Conference (Wellington, October 2000), pp 39-56. Autism NZ, PO Box 7305, Christchurch, New Zealand