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Abstract

In this article, we undertake a reflective narrative inquiry into the GimpGirl Community (GGC), an online group of women with disabilities. We explore 12 years of GGC activity through community archives and auto-biographic narratives of GGC organizers, to understand how these women actively created a safe and open space for like-minded individuals, how community members used diverse online technologies for community building and social interaction, and how these online tools allow some members to experiment with their notions of self and identity outside dominant discourses. Our

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analysis of the lived experiences of GGC members reveals how they challenge the boundary between 'abled' and 'disabled,' and enact agency beyond their marginalization as women and as individuals with disabilities.

Keywords

disabilities, online community, social media, virtual worlds, women

Introduction

The uneven access to Information and Communication Technologies (ICTs) within and between societies (the 'digital divide') remains a central issue in the field of Internet Studies (Katz and Rice, 2002). Debates, however, have shifted from the unequal diffusion of access between haves and have-nots to more complex socio-cultural problems underlying unequal access to information and ICTs. In examining this 'usage gap,' researchers such as van Dijk and Hacker (2003) have pointed out the importance of exploring what people actually *do* with ICTs, rather than investigating access issues. Among the various kinds of ICTs, the internet, which has become a 'mass medium' (Morris and Ogan, 1996), has become a major subject of empirical and qualitative inquiry. Several scholars (e.g. Nolan and Weiss, 2002; Haythornthwaite, 2008; Valentine and Skelton, 2009) have highlighted the need to explore how diverse social groups access internet-based tools and communities in their everyday life; how people develop and maintain social relationships through such media; and to what extent the internet enables people to interact within a particular society.

Along with the increasing academic attention to diverse internet usage in everyday contexts, research on issues of unequal access to online media is beginning to focus on the experiences of marginalized or under-represented groups, including people with disabilities (Chen and Wellman, 2005). In previous decades, the internet – due mainly to its relative anonymity and disregard of geographical constraints – was hailed as a technological antidote for previously disadvantaged or oppressed groups. It was thought to help such populations overcome challenges or redress power imbalances, enabling the formulation of alternative forms of public fora, or online communities (e.g. Rheingold, 1994).

For people with disabilities, however, research suggests that online experiences have both positive and negative consequences that are often not taken into consideration. Some researchers have viewed the internet as highly beneficial: as an interactive tool to educate women with disabilities about reproductive health (Pendergrass et al., 2001); as a communicative space to foster self-help groups among people with physical and mental impairments (Finn, 1999); or as a virtual haven in which disabled people can freely express themselves without the prejudice associated with impairments (Bowker and Tuffin, 2002). Other critical researchers have commented on the negative potential of the internet to reproduce and even reinforce boundaries between the abled and the disabled. For instance, in her study of ICT use by people with disabilities in Norway, Moser (2006) argued that current ICT public policy gears toward normalization, turning disabled people into 'competent normal subjects' (p. 383). Similarly, Bowker and Tuffin (2002), while recognizing the empowering potential of the internet for people with disabilities,

suggest that the anonymous nature of online interaction reinforces the standard assumption of normality based on a non-disabled identity. Dobransky and Hargittai (2006) also report that the relative lack of in-depth study into ICT experiences among different disability groups has produced inconsistencies within the existing body of internet and disability studies. They criticize the dominant tendency to collapse differing types of disability into one category.

Despite the diverse approaches to issues of individual and community use of ICTs, studies tend to under-represent people with disabilities as active community members and organizers. While some qualitative studies have partially included the voices of disabled people via interview and survey research (e.g. Valentine and Skelton, 2009), they often treat subjects as individual internet users with disabilities, rather than as those with a capacity to create and moderate communal activities. Also, most research has been conducted from the researcher's perspective, which has the inherent risk of representing the subject matter from a 'non-disabled' point of view. Few people with disabilities have reported how they conceptualize their everyday online experience and how they maintain and modify social interaction.

This study explored the key members, events, issues, and technologies of GimpGirl Community (GGC) (<http://gimpgirl.com>), which was founded in 1998 as a forum for women with disabilities, run by women with disabilities. We focused on the lived experiences of GGC members: how they actively shape and nurture this online community for like-minded individuals; how they maintain and moderate social interaction among members; and what path the community has taken in the past twelve years. The study could be considered a reflective narrative inquiry and learning exercise in which key members of the GGC took initiative in setting the research agenda, conducted their own inquiry, and organized and presented their analysis in collaboration with co-authors/academic mentors who wanted to help the group share their story with the academic community. By documenting the organizing efforts of GGC moderators and their learning experiences over the past decade, we were able to inquire into the connections between online technologies and the capabilities people need to develop and maintain communities.

Initiating inquiry

We were particularly interested in what initially drove GGC members to develop an online community, how the community solved problems, and how various online technologies (from text-based to more recent mixed-media virtual environments) were adapted to meet the diverse needs of members. Our investigation was inspired by the method of narrative inquiry: qualitative research that examines narratives to understand the meanings people ascribe to their experiences (Trahar, 2009). Narrative inquiry takes diverse modes of filed texts – oral, written, visual – as data sources to look for deeper understanding of 'lived experience' (Clandinin and Connelly, 2000; van Manen, 1997). We saw the value of how, based on various narrative elements, narrative inquirers interrogate how the life experiences of individuals get woven into a story, for whom and for what purpose, and what cultural discourses it draws upon.

One apparent advantage of conducting a narrative inquiry of an online group is the relative ease of retrieving detailed logs of the community in the form of digital texts. As Hine (2000) notes, viewing cyberspace as a collection of interactive texts allows researchers to 'follow the progress of development of a web site and explore the interpretations of those involved as to the capacities of the technology and the identity of the audience being addressed' (p. 52). For our inquiry, digital archives of the twelve years of GGC activity constituted archived texts that include postings to the community listservs, blog entries, minutes from staff meetings, and online dialogues among the members. Formulation of this article took place solely online with members in different parts of the world, and incorporated recent scholarly contributions from the group (Cole, 2009; Cole and Mancuso, 2009; Mancuso and Cole, 2009; Ospina et al., 2008).

Along with archival materials, we chose to focus on auto-ethnographic reflections of the founding member Jennifer Cole, as her experiences best portray the overall structure and development of the community. It is not unusual for an author of an auto-ethnography to consult with various other people and materials, but it is less common for multiple authors to agree on a single voice to represent a community. Lather (1995) used this approach and noted the challenges of telling stories on behalf of marginalized individuals, as well as the concomitant necessity to do so. Jennifer's auto-ethnographic writings were nurtured by online discussions and one-on-one dialogues between the co-authors, as they collaboratively reconstructed memories of the community. In so doing, we attempted to avoid a risk inherent to auto-ethnography to be solipsistic, simplistically using lived experiences as self-evident and authoritative warrants to support the claim, while 'pushing "other" voices out to the margins' (Trahar, 2009: 7). Although Jennifer's personal reflections placed her at the center of this inquiry, the collaborative co-construction of her auto-ethnographic narrative incorporated collective memories of the community, thereby constituting an interactive voice that reflected the inter-subjectivity between herself and the other GGC members.

Nonetheless, undertaking the auto-ethnographer's gaze appeared to be an extremely challenging process for Jennifer and her co-authors, since this method requires researchers, deeply embedded in particular cultural and social processes, to subject themselves to critical analysis (Young and Meneley, 2005). We faced repeated dilemmas related to objectifying personal experiences and communal narratives of the GGC. During collective composition of this article, we constantly struggled between 'we' and 'they,' simultaneously acting as participants and observers, and as administrators and active members of the community. To the end, we acknowledged the ability of auto-ethnography to put us in 'the driver's seat' (Lambek, 2005: 233), allowing us to engage in intense and critical reflection while remaining reflective and critical about our subjective positions. Our collective goal has always been to share the story of the GGC from the members' perspectives and, where possible, to ensure that their voices take precedence over the academic voice. All the GGC members quoted in this article agreed to use their real names as a show of pride and community spirit, supporting this project as the first step in a larger program of narrative inquiry about the lives of women with disabilities.

The following sections begin with the genesis of the GGC, the rationale for its formation, and its initial conceptualization and mandate. This is followed by an audit of the technologies and tools, from listserv and MOOs (Multi-user Domain, Object Oriented), through

LiveJournal, Moodle and Second Life, various interactions these tools supported and encouraged, and how these changed the structure and governance of the community. By investigating Jennifer's narrative in the context of various episodes and incidents in the collective life of the GGC, we explored issues of inclusivity and exclusivity crucial for maintaining a safe and open space for participants, as well as the experiments in identity construction performed by some GGC members. These experimentations presented a counterpoint to conventional assumptions about women with disabilities that construct them as asexual service recipients without autonomy or agency.

Genesis of the GGC

Inspired by her participation in the DO-IT program for teens with disabilities (<http://www.washington.edu/doit/>), Jennifer and her mentor Len Burns founded The Center for Breaking Away, a non-profit organization for disabled youth transitioning to adulthood. This organization originally housed the GGC project, but was dissolved after the GGC project outgrew the center. The GGC was founded in 1998 as a collaboration of young women with disabilities who shared a dissatisfaction with pre-existing services and communities, which appeared incapable of fulfilling the needs of these youth in transition to adulthood. For Jennifer, a chief motivation for creating the GGC was to fight back against abusive situations she had encountered, and to counterbalance her early heteronormous role of being a passive daughter/child with a disability. She noted in an online conversation with the co-authors:

I started it [the GGC] when I was 18 or 19 I think. Just after I left an abusive home. It started as me battling back against that and forming community to help each other through those tough times. Many people with disabilities feel like when we are no longer cute kids, we get thrust out into the world without much support. This is what the GGC was made for, to offer direct peer-to-peer support Interestingly, we came across many women who were just out of abusive situations or actively in abusive situations and I was so glad that they found somewhere to go and didn't have to create it.

The GGC was intended as an online-based group connecting isolated members with shared interests. Most of the founding members were teens who had met each other through the DO-IT program or similar organizations, and so the GGC was initially founded by and for young women, who created a safe and informal space for sharing ideas and experiences, discussing issues involved in the transition to adulthood, and for offering information and peer-to-peer support unavailable in formal settings. The domain gimpgirl.com was registered in February 1998; this was initially Jennifer's personal website, but was almost immediately given over to GGC. Jennifer was the first leader, though governance changed over time. She thought of herself as running and growing a non-profit.¹ The GGC website was one of the first sites dedicated to women with disabilities based on self-diagnosed disability, without restrictions on age, sexual orientation, or types of disability. The website included links to news from the disability community and resources for women with disabilities. Other areas showcased art and writing of members, as well as fun activities such as quizzes and polls.

Soon after the GGC was founded, staff realized that the site should embrace a broad community of women with disabilities who shared similar needs and ideas. Members shared a desire that initially inspired the founders to distance themselves from official institutions such as educational, social, and medical organizations that often had an inescapable impact on their lives, and the GGC provided a space for these women to be themselves, talk about what was important to them, and define their own terms of reference and agenda. Members were valued and respected, and the community has always included women with different disabilities of all shapes, sizes, ethnic backgrounds, and sexual orientations. The GGC consistently encouraged members to identify with the experience of being a woman with a disability.

In the process of building a strong community, the GGC has sought opportunities to educate members and the public about information relevant to the diverse lives of women with disabilities, as well as to encourage members to advocate for themselves and women with disabilities. Because GGC members had struggled to find a community in which they could feel a sense of belonging, it was difficult to reach consensus about how to conceptualize and co-construct a community that focused on and respected the particular needs of diverse members while avoiding isolating them or falling to the pressure of institutionalized norms. As the GGC gained more diversity in membership, its name became a subject of debate. While the GGC always stressed its inclusive nature and never focused on any particular type of disability, not all members were comfortable with the name 'GimpGirl' due to the nature of disability, society's treatment of disability, and the language around it. The GGC logo (Figure 1) also sparked controversy because it only appeared to represent mobility impairment.



Figure 1. The GimpGirl logo

The name 'GimpGirl' originated as a nickname Jennifer's friends called her when she was a teenager: '[The nickname] didn't have any particular meaning other than who I was, and a big part of who I am is getting beyond terminology, which still carries in what we do today.' By sharing her nickname with the group, Jennifer motivated herself and other GGC members to 'get each other through life' beyond any given terminology. Jennifer suggested that what underlies the active use of controversial language was a challenging spirit against conventional discourse surrounding women with disabilities. She noted:

[The term 'GimpGirl' was] Not offhand. I know even before we started [the group in 1998], people in the disability community were calling themselves gimps (mostly on the West Coast) and crips (mostly on the East Coast). It was a source of 'cheeky' pride While the language we use has definitely sparked some controversy, it is who we are and so it has withstood the controversy. Within the disabilities community there always seems to be some set of politically acceptable language that we are supposed to use to make people feel better, and part of our stand is that we can choose how we react to whatever language people use. Our goal is not to be popular or be politically acceptable, but to get each other through life.

Jennifer's subversive moniker also mirrored her expectation that the name and logo of the community would remind participants that they are the ones who give power to words, and would encourage them to distance themselves from the ever-changing 'politically correct' institutional language that defines and shapes much of the identity of women living with disabilities. Whenever the name or the logo was a topic of discussion, Jennifer referred to the two major focuses of the GGC – identification with being female and having a disability – and reminded the group that the community was intended to facilitate commonality among women with disabilities. GGC members and their families became increasingly accepting; one mother of a GGC member sent an email to Jennifer, commenting: '[At first,] 'GimpGirl' seems rude but when I think more on the term, it is upfront and confident and takes away any sense of pity.'

The growth of the GGC and use of online technology

One important characteristic of the GGC is its active search for, and implementation of, new technologies to facilitate member participation in community development and maintenance. The community has transcended any specific technology and has morphed through listservs, interactive virtual worlds, websites, blogs, and various social networks. Rather than abandoning old tools and moving onto new ones, the GGC has actively sought effective technologies to develop and deliver desirable content for its members. Before adopting a new form of communication, staff consults with board members and the community to see how many are already using a particular technology and how accessible they found it. The administrators then further research the technology with regard to usability and accessibility, to ensure that a benefit to some would not exclude others.

The social crowd and impromptu 'family' responsible for the genesis of the GGC initially interacted and socialized on SerenityMOO, which ran on servers of the Sasquatch Computer ISP, operated by Jennifer and Burns.² SerenityMOO is a text-based virtual reality environment with an object-oriented language and a more developed sense of avatar-based identity. MOOs are predecessors to systems such as Second Life and MMOs

(Massively Multiplayer Online Games) (Kendall, 1996; Sponaas-Robins and Nolan, 2005; Mazar and Nolan, 2009). MOO's text-based, narrative environment and codebase enabled participants to be more deeply immersed than other forms of chat available, and its tools were relatively intuitive for the time. When the founders decided to formalize the community, they held a series of staff meetings and events on SerenityMOO. However, the system had drawbacks, including accessibility problems, such as requiring a great deal of typing for interaction and quickly moving text that could be difficult to follow, depending on members' abilities. While it was easier to configure and customize than similar systems, it required a fair amount of technical ability to create a personal space and persona because it relied on typed commands. Still, it provided the GGC with a virtual location in which members could learn together and build a sense of shared place and community.

Along with SerenityMOO, the GGC set up email lists for discussion. The mailing lists were easier for lower mobility members of the community to use than the more immediate synchronous text-based environment of the MOO. The email discussion lists were also useful for keeping track of longer running conversations and larger topics, and allowed members better opportunities to reflect on how they presented their opinions and how they crafted their responses to others.³ The GGC launched three mailing lists within about the first year: Girlies, for young women with disabilities in transition to adulthood (started on 5 March 1998); QueerGirlies, for young queer women with disabilities (started 30 July 1998); and QueerLadies, for all queer women with disabilities (started 15 March 1999). BohemiGimps, an arts/culture-focused list, was added later (25 September 2003). At the time, mailing lists were the best way to promote maximum participation while allowing diverse threads for each sub-group. Topics were often individual and experiential, ranging from mundane to graphically personal. The administrators made a constant effort to create a safe and welcoming environment, and so many participants expressed a sense of commonality, acceptance, and empowerment.

The lists required a high level of maintenance. To ensure that participants were not 'flamed' while they sought acceptance, GGC staff members decided early on to moderate all lists and manually filtered out spam, chain mail, and other undesirable postings. However, despite these efforts, a fierce flame war erupted among members in spring 2002, when Jennifer and other GGC staff had left the list on autopilot for a five-day vacation. The following message was posted on the QueerLadies (QL) listserv:

Date: Sun, 24 Mar 2002 14:58:13 -0500 (EST)

From: Girl 1

Subject: QL: lesbian oriented site?

Ladies,

I'm just wondering ... is this not a site for LESBIAN women with disabilities [sic]? Perhaps it's just my own ignorance but why then are bisexuals and transgendered posting here?

As a lesbian with a disability, I wish to bond with and hear from others like me. I do not wish to sound harsh, I'm just confused. Sorry if I do offend anyone, I'm just confused as to what this site is meant for.

This and following messages posted by the original poster (Girl 1) sparked a controversy over the nature of the QL list and its membership. The list was intended to provide an open space for discussion, but Girl 1 raised a concern about the very 'openness' of the listserv by imposing her definition of 'queer.' Other members vehemently argued against her separatist viewpoint and even harassed her until she decided to leave the list permanently. Other popular members also left the list as a result of Girl 1's exclusionary attitude. Jennifer and other moderators returned to witness many hurt feelings and vicious emails overwhelming the community. They were disheartened about actively facilitating peer support between GGC members for some time, and found it difficult to believe that members who had struggled so hard for acceptance would attack others in this way. As Jennifer recalled:

[After the incident] I wrote a message to the list and apologized to everyone and explained what happened, and most of them were very glad to hear from me and were very confused as to why I had not been around. I tried to make amends with the people who had gotten their feelings hurt by [Girl 1's] exclusionary attitude, and convince them that that does not reflect how we feel, but they wouldn't come back because they had been battling against that attitude their entire lives and didn't want to chance it After this [incident] activity died off slowly. It really changed the tenor of our group for a long time. At that age such an incident made me feel very disheartened about running a support group, especially in the midst of my own life struggles.

This incident posed a difficult challenge to the moderators regarding inclusivity and exclusivity of the community; while they always have encouraged participants to freely identify with their experiences, they now undertook the responsibility to teach members how to respect each others' identity. This respect for the diverse ways each member constructs her identity online became a hallmark feature of the GGC, allowing our gender and disability to function as our primary unifying tenet. Facilitating such an inclusive approach required a more directly engaged administration by people who were willing to put time and effort into the development of a governance structure to coordinate communication and group activities. However, personal and professional conflicts were developing between a few founding members and all but Jennifer and a couple of mentors (board members) distanced themselves from the administration of the project. With so few staff members and so much work, governance became more relaxed and activity diminished for a time.

This relative lack of activity continued until the end of 2002, when Alejandra Ospina became more involved with administration. With Alejandra's active participation, Jennifer and other board members made an administrative decision to implement new technology to revitalize the community. On 18 July 2003, the GGC created an account on the LiveJournal platform (<http://gimpgirl.livejournal.com/>) in an effort to rejuvenate and diversify access and to reduce duties for moderators. The GGC later transferred all existing lists to this social networking platform, making the LiveJournal group the main venue for communal activities. In this system, users were able to

maintain their own accounts and benefited from a variety of available communities. LiveJournal also had community archives that were more immediate and engaging to new members. Maintenance was also easier, with intuitive, centralized tools for managing message moderation, and administrative access control. However, it still required sustained volunteer input and facilitation to remain an active form of community. Even after the GGC opened facilities in Second Life in 2008, the GimpGirl LiveJournal community remains the GGC's third largest community, with over 275 members worldwide who discuss wide-ranging subjects from bras and yeast infections to discrimination and victories.

The GGC's next major evolution came when Dr Mark Dubin of 3D Embodiment (<http://3demb.com/>) donated a quarter-sim parcel in Second Life, September 2007. The parcel was designed as a multi-use campus, with meeting rooms, a dance and pool area on the roof, an amphitheatre for presentations and events, a mall where members could sell items they had created, and a small apartment building where some members have homes. By February 2008, the parcel was fully developed and opened to the public, just in time for the GGC's tenth anniversary. This event was highly successful; members and supporters showed up to celebrate and hang out with their peers in this synchronous environment. After a decade of transitional homes, this incarnation marked a coming-of-age for the GGC, an all-volunteer group that had always worked on the fringe of the disability community without institutional support or formal funding. The launch was so successful that by March 2008 the parcel was redesigned by new volunteers to further increase accessibility and services. It also attracted support from Ryerson University's Experiential Design and Gaming Environment lab.⁴

While it provides many opportunities, Second Life also excludes a segment of the GGC membership because of accessibility and usability issues. Although progress has been made in recent years, Second Life remains largely inaccessible to visually impaired/blind members who rely heavily on screen readers to navigate, as well as members who have trouble processing the extremely visual interface, and those that cannot afford computers fast enough to run Second Life. In April 2008, the GGC adopted a relatively low-technology solution to the problems caused by this high technology interface, after discovering that the Quickfox Network had developed an IRC (Internet Relay Chat) to Second Life relay communications tool. The #GimpGirl channel (<http://chat.on.quickfox.net/GimpGirl>) linked to key locations on the GGC Second Life parcel, such as the weekly meeting area, allowing members on Second Life and IRC to chat in real time. An accessible IRC client was also installed on the GGC's website to reduce knowledge required to use IRC. The staff has made great effort to utilize available resources, and continue to push for universal accessibility.

Expansion into Second Life sparked another wave of development in membership, activities, and staff. Second Life helped bring in outside resources by allowing a broader network of supporters from the large group of pre-existing disability and non-profit communities. As social networks become more popular to keep in touch with friends and family (Wellman et al., 2006), more people and organizations are willing to venture into virtual environments such as Second Life. The GGC was initially composed of a close-knit community of women who knew one another, but now it has extended to a larger community.

Since expanding to Second Life in 2008, the GGC has worked to expand and govern the community, and is using online community building tools to reach a wider range of women with disabilities and form a rich and nuanced web of people and resources. It has hosted a series of online public forums on Second Life in which the members join professionals or scholars outside the membership; this has raised the GGC's public profile, engaged a wider range of dialogue, and clarified the complex issues surrounding women with disabilities. The GGC also extended its presence to Facebook and MySpace (later deleted due to inactivity and usability issues) on 17 February 2008 and later opened a Twitter account 2 April 2008. Meanwhile, the GGC redesigned its main website, utilizing the open-source Moodle software to add forums, a wiki, and a membership system. The website re-release was announced on 12 April 2008.

While Second Life helped administrators to rejuvenate the community, this open environment also invited occasional interferences by medical role-players, disability fetishists, and other disingenuous people. The GGC has always faced this kind of challenge when creating a safe environment where members can be vulnerable with each other and create bonds and community. In addition, as the membership has extended to more complex mixed-reality environments, Jennifer and other staff members became acutely aware of the shortage of human resources and strove to recruit more volunteers to fill administrative roles and offer fresh ideas. Many individuals expressed interest and promised to offer help from time to time, but frequently these volunteers did not realize how much work is actually required to provide peer counselling and run a successful online community. Staff members have found it extremely difficult to help volunteers realize that administrative work at the GGC requires a deep understanding of the responsible use and benefits of various technologies, basic knowledge of how to support others, and the ability to support or refer members in crisis. The GGC also faces special challenges because members are often struggling with their own health, abusive histories, and economic issues.

To conquer such challenges, the GGC staff has been developing infrastructures to help staff recruit volunteers with less time, computer capacity, or technical know-how. The internal organization of tasks can be broken into smaller, more manageable pieces and spread across many different people according to their individual skill set, allowing members to utilize the available help more efficiently. Additionally, the WYSIWYG (What You See Is What You Get) capabilities built into the GGC Moodle-based website have made creating and maintaining content easier as well as provided a central, private area for volunteers to coordinate efforts.

Beyond the myth of normativity: community, identity and technology

A consistent theme throughout this inquiry is the notion of being doubly marginalized: living as women and as individuals with disabilities. From a Foucauldian perspective, people with disabilities live immersed in a pathological discourse of disability, as an object of disciplinary power. They are forced to become the subject matter of professional groups, who constantly define the meaning of living with disabilities, resulting in

the systematic closure of opportunities for agency. On one hand, this view sheds a light on the reality of the abilism many GGC members face everyday. For them, the possibility of autonomy in day-to-day life is highly dependent on the willingness and ability of service providers and personal care assistants to see them as individuals with unique needs and goals. With potentially limited mobility and access to resources necessary to independently claim their own identity, they are often designated as the 'docile' population. On the other hand, however, as accurately claimed by Bill Hughes (2005), the Foucauldian view of (disabled) body as the source of regulation risks reducing various forms of embodied praxis of disabled people to the disembodied play of discourse (pp. 80–81). GGC members have strived to overcome the 'double silence' of women with disabilities by resisting the stereotypical view of living with disabilities, thereby claiming the status of subjects with agency (Ferri and Gregg, 1998: 433). The following extract from a staff meeting in August 2008 illustrates the moderators' effort to transcend conventional ideas of women with disabilities as asexual service recipients:

- Jennifer: Next item is: # Event planning
- Jennifer: so we have been talking about this on the forum, both the sexuality topic and the regular relationship event.
- Jennifer: For the relationship event I was thinking we could do a monthly open forum with everyone interested (except predatory ppl).
- Katherine: we could try an open forum – it might or might not work well
- Jennifer: Yeah it could go either way. I think we were planning a trial run.
- Krishanna: how will you figure out predatory people
- Jennifer: We define who is and isn't welcome. If we see predatory behavior, or even anyone there to obviously hit on girls, we have a security detail to ask them to stop or boot them, depending.
- Katherine: right
- Jennifer: We make it clear it's not a dating mixer. It's a constant struggle w/these events.
- Jennifer: did we answer your question Krishanna?
- Krishanna: yup!;)
- Jennifer: So, for the sexuality topic I wanted to put a lot of thought into it and have some presentations and materials planned out before we decided when exactly to have the sexuality topic considering the massive failure previous disability and sexuality topics have been on Second Life.
- Jennifer: It's a very important topic considering many of our fellow sisters with disabilities view themselves as either asexual (and not by choice or biology) or have some other extreme issue with their sexuality.
- Jennifer: And I think a lot of them really want to talk about it and want a safe place to share their feelings.
- Jennifer: One of our members was laughing at a show on relationships the other day, and said she could laugh because it had nothing to do with her. When I asked her what she meant she said 'because it has to do with dating and relationships.' I was kind of dumb struck.
- Katherine: Jenny: agreed. I would like to have some of our members who are in relationships of various sorts speak, too
- Katherine: or even just people who are actively dating
- Krishanna: but dating doesn't always mean sex.

- Jennifer: Agreed. I think we should put together a podcast. Maybe interview a couple of 'experts' on various topics relating to sexuality, and also interviews with some of our members who are actively dating to get their opinions and views.
- Jennifer: I totally agree, Krishanna. But given what I know of this particular individual, the reason she never saw herself dating was because she thought she was nonsexual because of her disability.
- Jennifer: Because society treats people with disabilities as non-human and therefore nonsexual.

(Staff members Jennifer Cole, Katherine Mancuso and Krishanna Spencer specifically requested use of their real names, as a statement of pride in their work for GGC.)

During this meeting, staff planned for an online event in Second Life, consulting about how to present and support alternative forms of identity construction, creating a space for members to share their experiences, problems, and solutions in the safest manner possible. Their positive attitude toward sexuality and dating echoes Barron's (1997) study in which young women with mobility impairments were reported to 'reject the traditional role of passivity and subservience, not only "the disabled" but also of women generally,' and instead 'strive towards being of assistance to others' (p. 234). For GGC moderators, emphasizing supporting and educating other members can be seen as a means of increasing their autonomy, freeing members from the role of passive and dependent recipient and enabling them to practice active agency beyond physical and social constraints. Striving for autonomy and identity has an impact off screen as well as on. The GGC community needs to be able to function as a permeable wall that can help protect members from predatory individuals, and also to establish clear lines of location of power and agency that define the community and model practices they will carry with them into other areas of their lives. The moderators are always concerned about the eventuality of predatory individuals entering the forum, and recognize the necessity to have well-defined purposes and boundaries to exclude inappropriate visitors. Women with disabilities have often experienced abuse, violence, and a severe lack of emotional support, so these walls are needed to help keep the members safe, allow them to be themselves and explore their own identities.

The attempt to maintain a safe environment, however, could also be exclusionary. While the community has successfully maintained an openness to all forms of disability by intentionally educating themselves about the needs of members, staff members have had to work in uncharted territory without models to emulate or apply. The need to create a safe and nurturing space for members must be balanced by a concomitant act of social engagement with larger disability communities, academic and medical communities, and the public at large. Because the goal of the community was to be inclusive and to give voice to those under-represented or marginalized, its model could not be fixed, but had to remain fluid and open to continual re-assessment and reconfiguration to ensure that power remained with all members. As the community has grown, the GGC has needed not only to consider the safety of members but also to reach outside its walls to interface with the public and advocate for public support and communication.

By using a variety of online tools, the GGC has helped members develop a capacity to perform as agents of self- and social transformation. The system also helps empower

participants to involve themselves in their own lives by providing information and broadening their experience with others in similar situations. Meanwhile, staff members are aware of the potential exclusivity of ICTs, due to financial requirements and other factors involved in getting online. To participate, members must purchase a computer and have access to the internet (financially difficult for many women with disabilities) and be technically savvy enough to interact with others via online-mediated platforms. This, according to Jennifer, may explain why many of the GGC members are 'computer geeks.' Despite these limitations, ICTs are the only way for many GGC members to shift discourse from an institutional/medical location to a community of their own. By doing so, Jennifer and other members have developed their own skills and strategies for using various forms of online technology, structuring community, negotiating participation, developing and maintaining community standards, and resolving conflict. Jennifer noted:

While online technologies certainly exclude a huge population, at the same time they are also very inclusive to many people because they reach into where they are. Many of us who are bedbound (like myself most days) and don't always have the same opportunities to be involved in face-to-face groups. Also for people who have issues socializing in face-to-face situations, either because of shyness or communication issues (for whatever reason), online environments are much easier.

Another challenge related to the use of online platforms is the issue of validity, stemming from the lack of face-to-face interaction among participants. While online forums are a good way to get a broad range of input from different people, participants accustomed to face-to-face interactions occasionally voiced concern about the GGC's fundamental reliance on online media. One former volunteer explained that some saw the GGC as 'not real enough,' because members rarely saw one another face-to-face. The concern is valid, because the GGC does not have an office, and members interact using text and avatars, sometimes supplemented by voice/video chat. However, the situation has been gradually changing, as the administrators have consistently encouraged other members to balance online and offline relationships. Drawing on her experience of gaining support from people she first met online, Jennifer explained how online technologies can help users overcome isolation in real life:

I think a lot of us who have issues [with socializing in face-to-face situations] eventually use [online platforms] to make friends face-to-face. Not all of us, obviously. But it's definitely a tool. In meetings we talk a lot about what people can do to meet friends face-to-face, how to find other support groups, how to socialize, etc. Not that I'm any great expert myself, but it's something we try to encourage to help people balance their lives.

Interactive platforms such as Second Life encourage members to work within a synchronous open-ended environment where they can directly interact with others via avatars. Having a visible representation of oneself on Second Life certainly allows members to explore their identity in a more 'realistic' environment. Members visualize their online identity in various ways; some members incorporate their real-life disabilities in their avatars, while others do not, and still others fluctuate from one choice to another. Alejandra changes her avatar's appearance depending on the representation she wants to portray,

using an avatar with a wheelchair when speaking to non-disabled people about the GGC, and an able-bodied avatar when speaking to her peers. Jennifer describes her avatar:

My avatar looks very much like me in real life, minus the signs of disability that I rarely display in Second Life because in my head I don't really picture myself as disabled. It's not part of my personal image of myself, not because I think appearing with a disability is in any way less of an option. It's just what feels comfortable to me most of the time.

Jennifer's story invites a particular and resisting reading of ICT policy, with the goal of encouraging disabled people to live 'normal' and 'integrated' lives (Moser, 2006). For Jennifer and other members, visual representations of self in the form of a Second Life avatar can vividly reflect how they understand their disability and identity in a variety of ways, as well as how they teach others about the disability community. Alejandra's occasional use of different avatars and Jennifer's disinclination to picture herself 'as disabled' exemplify how the Second Life virtual platform allows GGC members to express a subjective understanding of disability, unbounded by the stigmas ascribed to their real-life bodies. In other words, the ability to choose how to present themselves allows the members to express their identity in ways that work for them, without relying on conventional narratives of medical intervention or rehabilitation. Given Second Life's role as identity playground, the members become capable of creating their own meanings, to open up rather than close down the meaning of living with disabilities. By working toward transcending the myths of 'normativity' and thus being perceived as something other than helpless, they reconstruct their way of being-in-the-world as one of the privileges of life. For GGC members, who are often defined by institutions and medical definitions of their disability with limited opportunities for autonomous social exploration, ICTs represent an opportunity to move beyond externally imposed definitions of who they are, experiment with self-representation and forge their own sense of identity.

Looking forward

Conducting this inquiry has itself been a challenging learning experience that not only reawakened old memories of struggles, but also, for the first time, allowed us to see the GGC through a new, shared lens. The exploration allowed us to learn new ways to see ourselves, reflect on our accomplishments and better understand our challenges. Through the acts of retrieving, reconstituting, reflecting on and annotating twelve years of collective memories and archives of the GGC, in combination with Jennifer's personal narrative as the administrator, we aimed to create a document that would unpack and explore the particularities and shared commonplaces of this online community. The GGC has much to share on many levels: as a model of a self-sustaining online community; a community that maintains itself across a myriad of intersecting ICTs simultaneously; an example of how to resist institutional appropriations of identity and definitions of self for women with disabilities; and as an inclusive women-centered space that tailors itself to the needs of its members wherever they are and however they define themselves. The GGC is a unique community that has had the opportunity to come into its own and grow alongside the proliferation of the Web 2.0 phenomenon. Members of the community

have made choices regarding the technologies they use and how they integrate them in order to meet the needs of as many members as possible. Over the past decade, the GGC and its members have changed their lives, and have been shaped by the choices they have made in how they engage in ICTs. With the wider adoption of ICTs by society at large, we will continue to look for new ways in which to challenge institutional/medical discourses, as well as public perceptions of women with disabilities. As well, we consider the further exploration of various ICT tools central to our goal of bringing women with disabilities together in order, not only to share our stories and co-construct community, but to discover and create new opportunities for us to engage more fully with the world around us, both socially and economically.

Our collective contribution in the co-construction of this article very much follows the format of the co-construction of the GGC itself. Though a core of us became the authors, we represent a coming together of members and supporters of the GGC who were in a position to participate as we have – a temporary nexus in an ongoing dialogue – rather than the only possible configuration. We anticipate that future inquiry will focus on a wider variety of voices, both within the community and without. Accordingly, this article is the first step in an ongoing inquiry into under-represented voices of GGC members, which tell insider stories of the shared experiences of women with disabilities in socially networked environments. For now, the GGC leads into the second decade, building on this exploration of how we got here.

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Notes

1. After 12 years of activity, the GGC finally achieved this goal in January 2010. The GGC officially became a program of People Helping People (<http://www.phpnw.org>) to give the GGC 501(c)3 nonprofit status and the support of an organization with the same goals and passion to support the independence of people with disabilities.
2. In the 1990s, the GGC also produced printed newsletters mailed to accommodate those without internet access.
3. The lists helped document how the community developed over time; we are immensely thankful to GGC mentor Len Burns for his guidance and assistance.
4. Just before this article was published the GGC parcel in Second Life moved to the EDGE lab's sims at <http://slurl.com/secondlife/Research%20Edge/50/58/282>

References

- Barron K (1997) The bumpy road to womanhood. *Disability & Society* 12(2): 223–240.
- Bowker N and Tuffin K (2002) Disability discourses for online identities. *Disability and Society* 17(3): 327–344.

- Chen W and Wellman B (2005) Minding the cyber-gap. The Internet and social inequality. In Romero M and Margolis E (eds) *Blackwell Companion to Social Inequalities*. Oxford: Blackwell.
- Clandinin DJ and Connelly FM (2000) *Narrative Inquiry*. San Francisco, CA: Jossey-Bass.
- Cole J (2009) GimpGirl Community: Supporting the lives of women with disabilities. Paper presented at Sex::Tech Conference, San Francisco, CA, 22–23 March.
- Cole J and Mancuso K (2009) GimpGirl Community: Women with disabilities. Paper presented at 2nd Virtual Praxis, Online, 21–22 November. Available at: http://people.cohums.ohio-state.edu/collingwood7/minerva/conference09_jennylin.html (consulted March 2010).
- Dobransky K and Hargittai E (2006) The disability divide in Internet access and use. *Information, Communication and Society* 9(3): 313–334.
- Ferri BA and Gregg N (1998) Women with disabilities: Missing voices. *Women's Studies International Forum* 21(4): 429–439.
- Finn J (1999) An exploration of helping processes in an online self-help group focusing on issues of disability. *Health and Social Work* 24(3): 220–231.
- Haythornthwaite C (2008) Learning relations and networks in web-based communities. *International Journal of Web Based Communities* 4(2): 140–158.
- Hine C (2000) *Virtual Ethnography*. London: Sage.
- Hughes B (2005) What can a Foucauldian analysis contribute to disability theory? In Tremain S (ed.) *Foucault and the Government of Disability*. Michigan: University of Michigan Press.
- Katz J and Rice R (2002) *Social Consequences of Internet Use: Access, Involvement, and Interaction*. Boston, MA: MIT Press.
- Kendall L (1996) MUDder? I hardly know 'Er! Adventures of a Feminist MUDder. In Cherny L and Weise E (eds) *wired_women*. Seattle, WA: Seal, 207–233.
- Lambek M (2005) Our subjects/ourselves: A view from the back seat. In Meneley A and Young DJ (eds) *Auto-ethnographies*. Toronto: Broadview Press, 229–240.
- Lather P (1995) The validity of angels: Interpretive and textual strategies in researching the lives of women with HIV/AIDS. *Qualitative Inquiry* 1(1): 41–68.
- Mancuso K and Cole J (2009) GimpGirl community's best practices for facilitating an accessible community in a virtual world. Poster presented at IEEE Accessing the Future Conference, Boston, MA, 20–21 July. Available at: <http://ewh.ieee.org/conf/accessingthefuture/documents/mancuso.pdf> (consulted July 2009).
- Mazar R and Nolan J (2009) Hacking say and reviving ELIZA: Lessons from virtual environments. *Innovate* 5(2). Available at: <http://www.innovateonline.info/index.php?view=article&id=547> (consulted July 2009).
- Morris M and Ogan C (1996) The internet as mass medium. *The Journal of Communication* 46(1): 39–50.
- Moser I (2006) Disability and the promises of technology: Technology, subjectivity and embodiment within an order of the normal. *Information, Communication and Society* 9(3): 373–395.
- Nolan J and Weiss J (2002) Learning cyberspace: An educational view of virtual community. In Renninger A and Shumar W (eds) *Building Virtual Communities*. Cambridge: Cambridge University Press.
- Ospina A, Cole J and Nolan J (2008) GimpGirl grows up: Women with disabilities rethinking, redefining, and reclaiming community. Paper presented at Internet Research 9.0, Copenhagen, 15–18 October.
- Pendergrass S, Nosek M and Holcomb J (2001) Design and evaluation of an internet site to educate women with disabilities on reproductive health care. *Sexuality and Disability* 19(1): 71–83.
- Rheingold H (1994) *The Virtual Community: Homesteading on the Electronic Frontier*. Reading, MA: HarperPerennial.

- Sponaas-Robins R and Nolan J (2005) MOOs: Polysynchronous collaborative virtual environments. In Zemliansky P and Amant K St (eds) *Workplace Internet-based Communication*. New York: Idea Group, 130–156.
- Trahar S (2009) Beyond the story itself: Narrative inquiry and autoethnography in intercultural research in higher education. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* 10(1): Art 30. Available at: <http://www.qualitative-research.net/index.php/fqs/article/view/1218/2654> (consulted September 2010).
- Valentine G and Skelton T (2009) An umbilical cord to the world. *Information, Communication and Society* 12(1): 44–65.
- van Dijk J and Hacker K (2003) The digital divide as a complex and dynamic phenomenon. *The Information Society* 19: 315–326.
- van Manen M (1997) *Researching Lived Experience*. London, Ontario: Althouse.
- Young DJ and Meneley A (2005) Introduction: Auto-ethnographies of academic practices. In Meneley A and Young DJ (eds) *Auto-ethnographies*. Toronto: Broadview Press, 1–22.
- Wellman B, Hogan B, Berg K et al. (2006) Connected lives: The project. In: Purcell P (ed.) *Networked Neighbourhoods*. London: Springer, 161–216.

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