

**The Presence of Interlocutors**  
**vs.**  
**The Sites of the Internet:**  
**The Restricted Range of Disability Narratives**

*Ellen Barton*

**Introduction**

Despite a wealth of critical attention to new identity construction and creative narrative play on Internet sites (Turkle; Landow), many sites emphasize the continuity between online/off-line identities and focus on actual experiences from real life (Baym). Online health and disability support groups are of this latter type (S. Williams), as users go to the Internet to read and write narratives that help them learn about and cope with what may be a new identity in real life, one that is often unexpected and sometimes unwanted—cancer patient, chronic disease sufferer, mother of a child with a disability. Online support groups, though, exist in parallel with real-life support groups, which allows the comparative investigation of narratives of identity on and off-line. This article begins, then, with a descriptive question: how, specifically, are disability narratives of identity similar and different in online and off-line support groups? To investigate this question, I use Arthur Frank's well-known typology of illness narratives from *The Wounded Storyteller*, generalizing and specifying his categories in terms of disability narratives. I argue that real-life support groups with interlocutors actually exhibit a greater range of narratives than online support groups on the Internet. More specifically, I argue that real-life support groups allow what Frank calls chaos narratives, while online support groups do not. I speculate on the reasons for this discrepancy, concluding that the written language genres and socio-cultural frames of Internet sites are more powerful in restricting narrative discourse than the oral language exchanges and negotiable frames of real-life situations.

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This paper is drawn from an interdisciplinary project in linguistics and rhetoric investigating the ways that different discourses construct the social experience of disability in America (Barton). The project focuses specifically on families who have a child diagnosed with a disability, and investigates a number of settings within this experience: fieldwork for the project included participant observation and recording of medical encounters, interviews, and support groups. For this paper, the real-life data are drawn from a set of six support group meetings, the purpose of which is to provide information about special education law as it applies to public schools in the United States.<sup>1</sup> The support group is run by the metropolitan branch of a national disability organization, and is funded by the U.S. Department of Education. The families in the support group have children with a variety of disabilities, including physical disabilities, developmental delay, learning disabilities, and ADHD (Attention Deficit with Hyperactivity Disorder). Most of the online data for this paper are drawn from Internet sites run by a number of disability organizations.<sup>2</sup> The purposes of the disability sites are generally to provide information and support for families who have children with disabilities, including genetic disorders, autoimmune conditions, emotional/behavioral impairments, and ADHD. Online data for this paper are also drawn from a variety of disability activist sites.

### **Frank's Typology and Disability Narratives**

The theoretical framework for this paper is drawn from Arthur Frank's description and analysis of illness narratives. In *The Wounded Storyteller*, Frank presents a typology of illness narratives encompassing three generic forms: restitution narratives, chaos narratives, and quest narratives.

Frank argues that restitution narratives, stories of losing and regaining health, are the most common kind of illness narrative: the personal narrative of medical compliance in a successful rehabilitation from a heart attack, the story of cancer survivors printed in a glossy hospital brochure, the plot of television commercials for prescription and non-prescription remedies, etc. The restitution narrative is the preferred narrative of institutional medicine, with its focus on cures, as well as popular culture, in its denial of chronic illness, disability, and death. Frank argues that the restitution narrative is a master narrative with problematic sources and insidious effects: "People learn this narrative from institutional stories that model how illness is to be told . . . . Behind [these narratives] lies

the modernist expectation that for every suffering there is a remedy . . . . The idea that the changing physical capabilities caused by sickness require ongoing renegotiation of social obligations and personal identity is not part of [the restitution narrative]" (77-84).

The restitution narrative has its anti-narrative in what Frank calls chaos narratives. Chaos narratives have no upward trajectory of a plot with a restitution ending; instead, they are accounts of immediacy with a desperate underlying theme of despair. The identity of a chaos narrative is one of an individual "being sucked under" (97). Frank provides only one chaos narrative, but it illustrates the chief characteristic of chaos narratives, their "overdetermination of situation":

The speaker, Nancy, is a woman with a chronic illness as well as multiple family problems. She describes living with her mother who has Alzheimer's; her mother, she says, "just won't leave me alone."

And if I'm trying to get dinner ready and I'm already feeling bad, she's in front of the refrigerator. Then she goes to put her hand on the stove and I got the fire on. And then she's in front of the microwave and then she's in front of the silverware drawer. And— and if I send her out she gets mad at me. And then it's awful. That's when I have a really, a really bad time.

[T]he story has no narrative sequence, only an incessant present with no memorable past and no future worth anticipating. (99)

Chaos narratives are the most difficult narratives to hear, Frank observes, because they are so anxiety provoking: "listeners must face the possibility of this happening in their own lives" (101). Chaos narratives penetrate the denial of institutional medicine and popular culture and threaten everyone with the unwelcome circumstances of chaos and the possible identity of despair.

Frank deliberately privileges the final type of narrative in his typology, the quest narrative. Quest stories find life meaning in illness: "Illness is the occasion of a journey that becomes a quest . . . . [T]he quest is defined by the ill person's belief that something is to be gained through the experience" (115). What is gained from the experience varies—making major vocational and personal

changes, becoming an advocate, coming to a greater understanding of one's humanity—but what a quest narrative creates is a voice and identity for the teller that arises from a sense of purpose for being ill. Frank notes that most quest narratives are published works such as memoirs (of a life interrupted or ended too soon), manifestos for social action (to improve conditions for the ill and/or disabled), and automythologies (of the reinvention of self after massive trauma or catastrophic illness). Frank's examples of quest narratives are well-known in the literature of health and disability: he cites Gilda Radner's *It's Always Something* and William Styron's *Darkness Visible: A Memoir of Madness* as exemplars of quest memoirs, Irving Zola's *Missing Pieces: A Chronicle of Living with a Disability* as an instance of a social manifesto, and Oliver Sacks's *A Leg to Stand On* as an example of automythology. Frank also uses a traditional literary frame to analyze quest stories, Joseph Campbell's *The Hero With a Thousand Faces*, with its constructs of departure (onset of symptoms), the road of trials (course of illness), and return (with an identity as master of two worlds, the ill and the well). In comparing the three types of narratives in his typology, Frank foregrounds the quest narrative:

The quest narrative affords the ill person a voice as teller of her own story, because only in quest stories does the *teller* have a story to tell . . . . Restitution stories are about the triumph of medicine; they are self-stories only by default. Chaos stories remain the sufferer's own story, but the suffering is too great for a self to be told . . . . Though both restitution and chaos remain background voices when the quest is foreground, the quest narrative speaks from the ill person's perspective and holds chaos at bay. The quest narrative affords the ill their most distinctive voice. (115)

The quest narrative is the most sustained, the most reflective, the most literary of the typology. It is significant that Frank provides no quest narratives in oral or written language from everyday life; he suggests that a fully interpreted quest narrative may be a genre specific to literature (116).<sup>3</sup>

For an investigation of disability narratives in everyday life, Frank's typology must be made more general and more specific, since disability narratives are somewhat different from illness narratives and since narratives in everyday life do not occur within all three of Frank's categories. Because disability is characterized by

its permanence, the category of restitution narratives must be made more general and retermed success stories. Further, success stories must be divided into two, quite specific subtypes—popular success stories and activist success stories. Both success stories and chaos

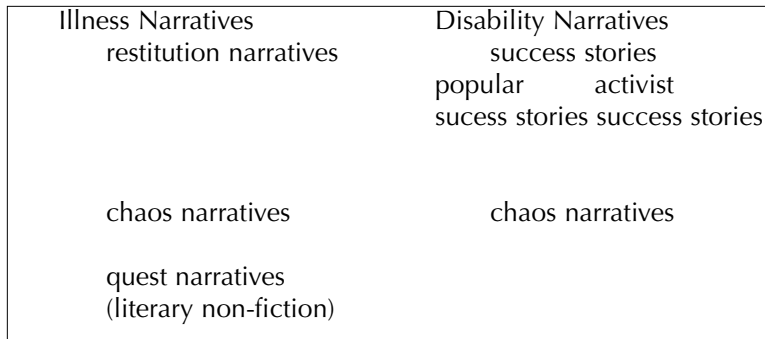


Figure 1

narratives were found in the everyday narratives examined for this study, but the genre of literary non-fiction quest narratives, it will be shown below, was not found in the collection of disability narratives in support groups on or off-line. Figure 1 depicts the modifications to Frank’s typology for the purposes of this study.

Popular success stories often occur in places like newspapers, magazines, and publicity from charitable organizations, with themes of conquering disability: curing or ameliorating it either through faith and prayer or through the advances of medicine, for example, or overcoming it by strength of individual character. This theme of disability overcome by individual character is a long-standing one in the popular press of 20th century America, as in the following examples from the *Reader’s Digest*. “The Boy Who Could Never Run,” for example, cried in frustrated defiance to his playmates, “I could run before, and I can still run—you guys just wait and see if I can’t!” (D. Williams 89). With the loving help of his family, this boy devised his own massage program, overcame the lingering effects of severe burns, and established the 1934 high school record for the mile in Kansas. In another example entitled “The ‘Quad’ Who Won’t Quit,” a teenager paralyzed in a wrestling accident concludes, “Everybody is responsible for his own actions. When the chips are down, what you do, and are, is up to you and you alone. He determined that, win or lose, he would turn in a performance that he and his family could be proud of” (Rankin 84). After grueling rehabilitation, this young man entered Harvard, joined a jazz band, learned to paint with a special brush, and began to contemplate a career in rehabilitation.

Perhaps not surprisingly, popular success stories are often abhorred as demeaning by contemporary disability critics and activists, who argue in activist publications like *The Disability Rag* (Shaw) and scholarly publications like *The Body and Physical Difference: Discourses of Disability* (Mitchell and Snyder; cf. Longmore's essay on charity telethons) that individuals or families who participate in this popular narrativization of disability are Tiny Tims, supercrips, and sell-outs presenting themselves for able-bodied readers' pity and praise, willing victims of society's view of disability as a defect and a deficit. Critics and activists thematize a different perspective on success in narratives that define disability as a social condition of segregation, offer an identity of resistance and activism, and issue a call for social action to enforce civil rights. For instance, in a creative narrative from *Ragged Edge* (formerly *The Disability Rag*), Cass Irvin, a prominent disability activist, tells of reclaiming the room where she spent her isolated childhood in "From the Kitty Room." The point of the narrative, though, is to generalize her individual case to describe the segregation of the disabled and call for those with disabilities to unite under the activist umbrella of disability culture:

I remember when I was twelve noting in my diary that I had spent a whole month—30 days—in this room. Never leaving my bed, actually. I was a classic case of "bedridden." It was easier on my mom if I didn't get out of bed and up in my wheelchair. So I didn't. This is not a big room. It's smaller still if it's your whole world. For too many years, it was my whole world . . . . [T]oo many of us think of ourselves as not disabled. Thus we think we can't connect to disability culture . . . . Growing up with a disability in America is to experience unconventionalism, confinement and oppression. We have to acknowledge that part of our culture has been oppression: physical, economic, educational, institutional—oppression not always acknowledged; but real nonetheless. It's sad that part of our past was painful, but it's a tragedy if we don't learn from it. That's why disability folks are coming together and getting involved. That's why we're chronicling and reclaiming our history, why we're teaching disability history, and why we're starting to write about it from our perspective. We are building a disability family, celebrating our culture. (24, 26)

In this narrative, identity is defined as developing pride in one's disability and success is defined as becoming an activist to forward a perspective on disability as a civil rights issue in contemporary American culture.

In the contemporary climate of English studies, it is at first tempting to see popular success stories of disability as versions of Frank's restitution narratives and to see activist stories as quest narratives that have achieved a critical and political consciousness. But I see them both as kinds of success stories, disability forms of the restitution narrative, because each tradition argues that an individual becomes a success by virtue of adopting a particular perspective on disability. Popular success stories are stories of assimilation, offering the identity of individual achievement; activist success stories are stories of individual and collective resistance, offering the identity of activist pride. Success in these stories is defined very differently, but both traditions present narratives in order to define an identity within a particular social and ideological framework.

In this work, I will contrast success stories to chaos stories, because these are the kinds of stories I found in my research on support groups in everyday life. By generalizing Frank's typology into a binary system, I do not mean to imply that I don't think quest narratives exist or that they do not serve the purposes that Frank describes. In fact, I agree with Frank that quest narratives might only be possible in sustained, literary form, and that the quest narrative is the development of an individual voice (and not an ideological identity as in the success stories described above). I would cite the literary non-fiction of Nancy Mairs, for example, as quest narratives that arrive at a profound interpretation of the meaning of disability in an individual life and in society. But I did not find narratives of this interpretive depth in my data, either in the real-life or the online support groups, nor did I find this kind of depth in the narratives of journalism, either in the popular press or the activist press. In fact, I found that these ideological themes of success stories as described above, identities of achievement and identities of activism, were narrativized without significant variation again and again. For another piece under development in this project (Barton, "Rights"), I collected all of the narratives concerning disability that appeared in the *Reader's Digest* since it began publication in 1922; I also collected all of the narrative pieces that appeared in *The Disability Rag* since it began publication in 1980. I found remarkable similarity in themes across narratives across time: the *Digest* promotes assimilation by virtue of the individual American character; the *Rag* privileges resistance to American

stereotypes and social action in the realm of civil rights. This is not to diminish the importance of these everyday narratives and their themes; they, too, forward important meanings and interpretations, but not ones that are as fully and individually developed as those in published quest narratives. So for the purposes of this paper, I have combined popular and activist narratives in the category of success stories in contrast to chaos narratives, and I will now show how these categories of narratives occur in real-life and online support groups.

### **Narratives in Real-Life Support Groups**

Real-life support groups vary tremendously, from informational presentations by medical and service professionals at formal meetings (Gubrium) to casual conversations among strangers in a waiting room forming an ad-hoc self-help session (S. Williams). The support group I observed lies in the middle of this continuum. It has a formal framework, including its funding by the U.S. Department of Education and its sponsoring organization of a national disability agency, and it has trained facilitators, Delores and Jeanne, themselves parents of children with disabilities, who follow a semi-formal curriculum in presenting information about special education law to participants.<sup>4</sup> The support group meetings, however, often became informal, with facilitators and participants sharing stories, exchanging gripes, and offering advice. Narratives of identity played an important role in both the formal and informal discourse of the support group. For example, facilitators regularly repeated narratives that illustrated aspects of the curriculum, describing and ascribing an identity of parents as advocates for their children. And sometimes facilitators and participants would ignore the curriculum and simply tell stories about their experiences in this identity, their successes, failures, and frustrations in working with the school system.

The narratives that were presented as illustrations of the curriculum were the facilitators' version of success stories because the narratives incorporated the themes and identities privileged by the group, specifically the theme of working with special education law and the identity of being an advocate for the child. This theme/identity configuration of knowing the law to advocate for the child regularly occurred in facilitators' discourse, as in this narrative of her son's changing diagnoses by Delores:<sup>5</sup>

- (1) D: My son is 19. He goes to ((name of school)). He is classified as having a learning disability. He was first—he



was class—he was diagnosed as schizophrenic and then that went away. Don't ask me how but it did. Then he was classified as emotionally impaired. That went away. He did do—I don't know, you know—Now he is classified as learning disabled and he is in a resource room program. Oh, in a resource room program. So this is what I'm telling you if you—Knowledge is power. If I had known one (rule) when I first—when he first got his special education, things would have been different for him but I didn't know. But see now you have a chance 'cause it's PTIs now you know. It's Parent Training and Information Centers here for you to learn and know from parents.

Delores's narrative here is not presented as a classic success story; in fact, Delores's point is that if she had been empowered by knowing the law she would have been able to advocate more effectively for her son during his bumpy road through the special education classifications for children with disabilities. This narrative, however, is an anticipatory success story ascribing a specific identity to the support group participants, who will have the information and resources they need to become empowered parents who can advocate for their children and make their stories more successful ones.

In many stories told by facilitators, the events are based on the adversarial relationships parents can have with school professionals who do not automatically treat them as experts on the educational needs of their children, but the resolution of the narrative describes the successful results parents can achieve in these relationships if they know and use the special education law as advocates for their children. This is the trajectory of Jeanne's narrative about her son with cerebral palsy:

- (2) J: ((Mike)) is the one who wanted to home district. When I approached my district they said well ((Jeanne)) he can come home. He is not getting occupational therapy, and he is not getting physical therapy, he can go to a resource room. Trust me they had to contract a physical therapist and a occupational therapist. ((Mike)) is in the eleventh grade and still receives speech because he needs it for the speech and language. Now ask me if they like it. No they don't. I really don't much care what they like and I don't mean that mean. My son is entitled to what the law says and you will quote the law.

That's why you will never ever go into a meeting and quote somebody from ((name of organization)) or somebody from ((name of organization)). You say the law says and no one is above the law and that's just plain facts.

Like Delores's narrative above, Jeanne also presents an anticipatory narrative of success for support group participants who know and use the special education law as advocates for their children.

Participants in the support group also tell success stories in terms of the themes and identities privileged in the group. For example, the following parent offers an account of her attempt to address her son's difficulties by requesting an evaluation under special education law:

- (3) P: Now that's similar to—like ((Devon)). My son do not steal. He's into things. Just gotta keep busy. He's chewing on his clothes. He's chewing on paper. He's—I watch him. And I—I had to go and find out these things (by) myself. And I had the school do a psych test on him. To see that he was intelligent up here. So they would quit failing him. 'Cause he would just be falling through the cracks(s). And I wasn't gonna stand by and let this happen.

The mother's identity here is that of the pro-active parent who takes action in the face of an apparently incompetent and indifferent bureaucracy. Another parent tells a story of his success in using the threat of the law to have the school district assign a sign language-qualified speech therapist for his son:

- (4) P: If I could just say something regard to speech. What—what we did was—About a year and a half ago we saw that there was a problem. Two years ago we got a very good speech therapist to start working with our son and then took her with us to the IEPC ((Individualized Educational Planning Committee)) and literally threatened to sue 'em because their—their speech therapist was incompetent in least in terms of trying to meet our needs and they had (a bad speech therapist).
- D: You have the right as a parent to challenge either the credentials of that teacher if it isn't up to what your child needs. They have to get someone who is.

- P: Yeah, essentially the—the three and a half year old could do three or four signs in a row and none of the speech therapists could do that.  
(laughter)

This narrative ends with a joke and laughter, as everyone in the group recognizes how difficult the school system can be and how persistent parents as advocates must be.

All of the narratives in (1) - (4) are success stories, with narrative resolution and identity defined and thematized in terms of the group—successful use of the law by parents who have become advocates for their children. The facilitators' narratives in (1) and (2) track very closely with the curriculum of the meeting, and the participants' narratives in (3) and (4) follow the facilitators' model.

Sometimes parents tell narratives in order to ask a question, as in the following example:

- (5) P: There are some—There are some questions on that LRE ((Least Restricted Environment)) (in our) district and uh one of the things that keeps happening is that they put—Say in the third grade they'll take a half dozen children and put them all into one teacher's classroom—a classroom of thirty and just overwhelm the teacher which in my opinion is not the right thing to do because you put undue burden (in) a regular classroom environment and 30 students is awful . . . . I seem to want to distribute those—uh, like if there is three third grade classes—in terms of putting two children in each of those classes to—to even it out. Um, is there something in terms—in the law regards to how aides or paraprofessionals are paid for to—you know, with their need to provide this least restricted environment.
- D: The only thing we have is parents and this is if it's written in the IEP that a paraprofessional or aide is needed in that classroom . . . that's when they'll do it. That's—the only point I can make is it's got to be written in the IEP. Nothing else is even considered except for the number of classes—number of kids in the classroom.

Here, the parent tells the story of a situation in order to ask a question (a question-narrative, it could be called). The facilitators answer the question in terms of a successful outcome, though, emphasizing the theme of knowing and using the law to obtain the

desired outcome, anticipating a success story for the advocate-parent.

It is, however, in the conversational discourse of the group that chaos narratives can arise. Facilitators do not deliver chaos narratives. All of their narratives, even though they can recount horrific events such as Delores's son's chronicle of misdiagnoses, end with the affirmation of the identities and themes preferred by the support group—becoming a knowledgeable advocate who can successfully use the special education law. Participants, however, sometimes present chaos narratives, defined here as narratives of difficulty that are not thematized as success stories in terms of the group. These chaos narratives describe the frustrations of trying to work with the school system or the difficulties of parenting a child with a disability in the overdetermined, hopeless way described by Frank. The identity in these chaos narratives is not the pro-active advocate-parent taking action on behalf of her child, but the frustrated, angry, or helpless parent unable to change the world (or, specifically, the school system). The events in the narrative do not lead to a successful resolution, but recount inaction, inattention, and inability to improve the situation of the child. And, as Frank would predict, these chaos narratives are not well received by the facilitators of the group, who intentionally interrupt and reformulate them in terms of the themes and identities of the group.

The following two examples are chaos narratives from a white, middle-class mother, the first characterized by its relentless rhetorical questions and its moments of angry incoherence, the second characterized by its frustrated hopelessness:

- (6a) P: But how can you—I called the special ed director of ((name's)) school district (and) told her the detention problem for behavior was because of the self esteem and, you know, (what) was going on at school. I've had—asked the school to change this because I had him privately tutored. How can you flunk special ed? How can you go in with good grades and (then) you flunk special ed? So she is telling me that (it's) not special ed's problem that (pertains) to the school and she just shut the door right in my face. Now you tell me who the behavior problem is. From the frustrations because he is not getting what he (is) supposed to be. To learn how to teach and if you are going in and flunking. You call—I call her and she's calling me on her car phone because she is too busy to return my calls and

she could only talk to me (then). Then she is at the point of where she designates—and has to cut me off. Well, that's between the school—

J: You know what. There's a chain of command. You go to the teacher, you go to the principal, you go to the director, then you go to the superintendent and when the superintendent doesn't do anything then you come to the county. If the county doesn't do anything then you go to the state level. That's exactly— So my only thing is if you get before the judge and I tell people it's not like Judge Wapner, this is real court, guys.

(6b) P: When I walk in that school and nobody wants to talk (to) me, they all run—

D: It's too bad that you have to be so adversarial. That's—that's the part I—I get tired. If you('re) like me you get tired. You get tired of the struggle but you figure your child needs an advocate and if you do not advocate for the rights of your child no one else will so we have to do it.

Both chaos narratives are interrupted in order to turn to specific information and general advice in terms of the themes and identities of the group. In (6a), Jeanne turns to a specific discussion of the law, describing the official chain of command for pursuing complaints about special ed. In (6b), Delores turns to the identity of advocate, affirming its difficulties, but insisting on its necessity. The chaos narratives are reformulated into potential success stories based upon the parent's move away from the conditions and identity of chaos and towards the actions of advocacy.

Sometimes, however, chaos narratives can seem to take over the discourse of a meeting. In the following examples, the central city African-American mother's identity is one of despair, reflected in her thematic repetitions—*I'm back where I started from, I'm at the end of my rope*:

(7) P: The teachers when my son ran away from his school— When I had to transfer him—His file—I'd have known about the attention deficit. And he's been to five different schools. And now the school he is at now. I don't want him there. I don't want him to go to that school. I want him to be into a type of program, OK. He just

outta the hospital last month. I want him to be in a— They told that he could be as a outpatient, you know. At that facility. Or maybe somewhere else. But ((name of Medicaid insurance company)) doesn't pay for it. So therefore he's back—I'm back where I started from.

D: [Right

P: [That's another reason why I write that letter? I have it typed. Because the woman helped me downtown. She helped me to get my son into the hospital. And the medication that he needed. After five years, you know. But still—I'm back at the drawing board. I'm right back—I told him, I said, I feel like I'm at the end of my rope. I say— ['Cause I'm not getting any help—

D: [You gonna have to make the IEP work for you.

This was not the only chaos narrative presented by this particular mother. Through a process of narrative escalation, she manages to capture the floor for a remarkable twenty-six narratives, dominating the discourse of the meeting. She offers narratives of school suspensions and expulsions and escalates to narratives of suicide and schizophrenia, all presented within her identity of a mother without resources:

(8a) P: I have went through so much with ((Devon)). And the other four years. But just this year, I have been through so much for him. That I'm finding out more and more things, you know, about ((Devon)). Like with the— when they hospitalized him. And when they kicked him out of school.

(8b) P: It might have been last Thanksgiving. 'Cause it was two days before Thanksgiving. And I told him, I said, you and your brother go out and stop running through here. I'm trying to chop up these onions. Chop up, you know, this stuff for potato salad. And macaroni and cheese. And when it was real quiet—And I said, oh, I said oooh. They're sounding quiet. He's down there hanging by a rope. And his little brother helped him down. They could have killed themselves.

This mother emphasizes the theme of helplessness and the identity of hopelessness in multiple chaos narratives that receive minimal responses from the facilitators. The narratives recount events with-

out any resolution, without any reference to the advocate identity that the group sees as effective in addressing these troubles to head for success. The facilitators try to interrupt each time, but usually have nothing more to offer than another repetition of the group's theme of working with the law in the IEPC, as shown in (7). By the time the narratives in (8) occurred, this mother had worn down the facilitators to the point that they simply let her run on.<sup>6</sup> In this meeting, ordered discourse has disintegrated into the apathy that is created and sustained by chaos and its telling.

It is possible to critique the support group facilitators for not 'listening,' in Frank's terms, to the chaos narratives, to see the support group as, in fact, providing no support to its neediest participants, whose lives as parents of children with disabilities may be additionally complicated by poverty and other social and personal problems. But this is, perhaps, to develop a facile critique too quickly and to ignore the facilitators' legitimate purposes and intentions in trying to turn chaos narratives into success stories by promoting a change in identity to parent-advocates. The facilitators resist chaos narratives, it is true. But that is because they see their purpose as turning parents away from reactive despair and towards pro-active advocacy, and one discourse-based means to do that is to appropriate chaos narratives and reformulate them in terms of the themes and identities of the support group. As Delores and Jeanne summed up in an interview, "Because our job is to teach what the law says . . . . [W]e tell the parents to be your child's own advocate."

There is much more to say about these chaos narratives, but the important point for the argument here is that chaos narratives can be a regular feature of support group discourse when the support group is one in real-life. This is not necessarily the case in online support groups.

### **Narratives in Online Support Groups**

Like real-life support groups, online support groups also vary tremendously, from professional Web sites sponsored by commercial firms like *drkoop.com* to amateur home pages posted by families who have a child with a disability (Chase). To try to collect data that was roughly comparable to my real-life data, I visited online sites that were both informational and conversational (so to speak); in other words, I selected sites that included a fairly significant informational component as well as an invitation for users to give and receive support by participating on bulletin boards or in

chat rooms. I found most of these sites by jumping off from overview sites sponsored by disability organizations, such as the National Parent Network on Disabilities/NPND ([www.npnd.org](http://www.npnd.org)), or sites sponsored by critical and/or activist organizations, such as the Society for Disability Studies ([www.uic.edu/orgs/sds](http://www.uic.edu/orgs/sds)).

As in the real-life support groups, narratives play an important role in both information presentation and conversational sharing on these sites. Some narratives were thematized very closely with the information presented on the site, while others were simply stories of everyday life. But these stories, seemingly without exception, were success stories, in both the organizational and activist sites.

Let me begin with a set of examples that mirror the data from the real-life support group almost exactly. The following narrative was posted in a genetic disorder site under the title "Pre-School Disaster":

- (9) P: I have a huge problem. ((Theresa)) started preschool this week and I'm concerned about her placement. I went with her on the first day and found a classroom with no equipment for her. There were 15 kids in the class (which seems like a million to me). All were walking, talking, communicating, etc. I couldn't even tell that most were even disabled. The other children were SO much more advanced than ((Theresa)). They all sat on regular chairs (and went to the correct color as directed!!). The teacher strapped ((Theresa)) into this wooden thing that didn't help a bit. We went outside to play and the teachers sent the children down this HUGE slide. My stomach turned over imagining ((Theresa)) being sent down, not knowing what was going on, and flipping around (and off) half way down!! They decided to pull her around in a wagon with NO sides. I stopped that. One tug and she would have been on her head on the cement. Then inside for snack. (All the children washed up as told.) NACHOS!!! We are lucky to get ((Theresa)) to chew applesauce. I am scared to death imagining what will happen when I'm not there. She could be stuck in a corner and forgotten or hurt. My problem is this . . . I'm worried that if I call and complain about her placement that she will be put in a classroom where she isn't challenged (and boy, would she be challenged in this one!). I feel like she needs



more individual care than she is receiving in this classroom. I know a lot of you have said not to underestimate our ((children)) and I'm trying not to. Does she belong here and should I just "let go" and cut the apron strings???? Or am I justified in my huge panic? I would appreciate any suggestions!!!

This mother's lengthy question-narrative generated a string of seven responses (a fairly typical response level for online support groups). All seven recommended that Theresa's mom become an advocate for her child. Responses from Nancy's father in (10a) and B.T.'s mother in (10b) are typical:

- (10a) P:I would say, first of all, that your concerns are not unfounded, especially those that deal directly with ((Theresa's)) physical well-being (the slide, the wagon). It seems clear that the classroom staff needs to be educated about her abilities and what their limits are in working with her. I would think that many of your concerns could and should be addressed in her IEP (Individual Education Plan). Do you have one? This is a federal, not state, requirement, as I understand it, and spells out exactly what ((Theresa's)) goals in school are, as well as the steps that will be taken to reach them. It is a legally binding document, and **MUST** be signed by both the school and the child's parents. It is our primary tool for wielding any kind of leverage with schools, teachers, administrators that don't "get it" with regard to what we and our kids really need from them. ((account of his child's preschool placement)) ((Nancy)) seems to be inspired or motivated to want to do more.
- (10b) P:I would love to say you are not over reacting but hopefully it has been told to you enough. You are your child's voice and if you do not speak up for her no one else will . . . . With education, courtesy and politeness, I am sure you and the school system can find a workable and beneficial solution for your very precious little one.

Delores and Jeanne could not have put it better. Like the parent in (4), also a father, the success of Nancy's father's story in (10a) is based on his being an advocate for his child using the special education law, an identity he ascribes to Theresa's mother with his *our*

and we references towards the end of the post. Like the facilitator in (6b), also a mother, B.T.'s mother's assurance in (10b) that the work of being an advocate is worthwhile is presented as the path to success.

Despite its urgent tone and wealth of alarming detail, it is important to note that the narrative in (9) is a question-narrative, much like the one in (5). It is not a chaos narrative. Theresa's mother is describing a stressful series of events and referring to her panic, it is true. But the narrative includes many signs that she is not simply rehearsing the overwhelming immediacy of parenting a child with a severe disability. She actively affiliates herself with the identity of the group (*I know a lot of you have said not to underestimate our ((children)) and I'm trying not to*); she is ready to take action, although she is concerned about implications (*I'm worried that if I call and complain about her placement*); and her request for help is upbeat (*I would appreciate any suggestions!!!*) an indication that she is ready to act on behalf of her child. The responses affirm her pro-active identity, focus it in terms of advocacy, and recommend the standard solution of knowing and using the special education law. This narrative, then, is not substantially different from the (potential) success stories in (1) - (5), and is significantly different from the chaos narratives in (6) - (8).

In my journey through Web site support groups for parents of children with disabilities, I found success stories again and again, with varying levels of sophistication. The Internet is full of narratives with titles like "Family Success Story"; "A Day in My Life" (not a chaotic one, I would point out); "Discovering My Child Had ((Disability))" (first you grieve and then you learn); "Healing Broken Dreams"; and "Slowly Climbing the Mountain." A number of the narratives are simultaneously submitted to Web sites and to popular disability-parent magazines like *Exceptional Parent*. In addition to the theme and identity of advocacy, the online narratives reinscribe other familiar themes of mainstream success for families who have children with disabilities. The narrative in (11), for instance, tells of disability as a blessing in an otherwise normal life:

- (11) P: My daughter, ((Annie)), was diagnosed with ((condition)) last February . . . . I was so devastated. She was only 19 at the time. ((Annie)) had never been sick her entire life . . . . This ugly disease progresses so rapidly . . . . ((Annie)), now 20, is so emotionally strong and positive. She keeps me strong. On days where I want to cry and blame God, she laughs, continues to enjoy

her life and her friends, by not giving up and just continuing to LIVE . . . . I thank God for her wonderful attitude. She even said to me that we are Blessed. Yes, we are Blessed because we have so much love in our family.

((this post has a clip-art graphic of a little girl angel))

The narrative in (12) tells a familiar tale of parental expertise ignored by indifferent professionals:

- (12) P: I took my son to six different specialists. I knew there was something wrong. Six different times I was told, in varying degrees of hostility, that I was imagining things, inventing scenarios, even accused of Munchausen by proxy (a charming thing to hear at 8 AM). On finding the seventh expert, who observed my child for exactly five minutes, I finally got what I had fought so long to hear: a diagnosis. "Your son is classically ((disability)). There is nothing I can do. I suggest YOU find the name of a reputable institution and surrender him to the state before he destroys your life." That was the sum total of the session. The ((doctor)) who said this to me was not a crusty codger of the old school, either, but a woman my own age, represented as a progressive thinker . . . . Please don't lose confidence in what you observe in your own child. You are the hands on expert, having logged in countless hours of trial and error intervention and observation on this particular child. Impress that fact on the experts . . . . You are advocate #1 for your child . . . . I've been at this business for nine years now.

Again and again, though, as shown in (12), the success story is based on the identity of parents as advocates. The online and offline support groups for parents of children with disabilities seem virtually identical in this regard.

Internet sites with support groups run by disability critics and activists present a different kind of success story, but here, too, the presence of success stories is the rule. For example, one of the most famous disability narratives online, linked to and from multiple activist sites, is a copyrighted piece by Laura Hershey, a former disability columnist from the Denver Post, who also posts a monthly "Crip Commentary" on the Web. "From Poster Child to Protester," which also appeared in a small general-interest journal,

is virtually identical to Cass Irvin's "From the Kitty Room" cited above:

- (13) At the age of eleven, I was enlisted into this role of cheerful victim. I was a Poster Child. In 1973-74, I became a mini-celebrity, appearing at fundraisers throughout Colorado. I learned to smile whenever a camera appeared, and to say "thank you"—in other words, I learned to look, sound, and act cute and grateful. And on Labor Day, I became a prop in the TV studio where the local portion of the telethon was broadcast. To whole families, driving by to drop their contributions in a giant fishbowl outside the studio; to the camera's blinking red light; to the anchorman who squatted next to me, holding a huge microphone in my face; to everyone, I gave the same cute-and-grateful act, because that's what they wanted.

So I am no stranger to the telethon. And in the two decades since then, the telethon doesn't seem to have changed much. I watch it every year, just to make sure. It's still chillingly familiar. The sappy music, the camera close-ups of wistful faces, the voice-overs telling us about that person's dream to walk someday, the tearful stories told by parents "devastated" by their children's disability, and the contributors coming forward in droves—it was all just the same as I remember it.

But some things HAVE changed; I have changed. I don't know what my politics were as an eleven-year-old, if I had any. But my politics now—which are not merely political but also personal, spiritual, and practical—have led me to question and ultimately reject most of the values which the telethon represents.

Like Irvin's piece, this narrative is embedded into a larger analytic essay, with the narrative line leading towards a political self-realization, a proud identity as an activist, and a recommendation for social action.

Coming to this political identity is a success story repeated in activist disability sites, posted again and again in the exchange sections of Web sites. The level of sophistication varies, as it does across the popular success stories above. The following life-story narratives, for instance, come from a support group that asks users to climb up on a 'soap box' to discuss issues of disability; these

examples are excerpted from a thread discussing terminology and labels. The poster in (14) combines what seems like a fairly limited understanding of the pride theme with the popular blessing theme:

- (14) P: hi! I've just finished reading some of the soap box messages; I (must) say that I don't mind being called physically-challenged (I was born with ((condition)) and walk with crutches) or even disabled. however, the one term that I do hate for people to use is "cripple". it's such an ugly word . . .don't you think? Anyways . . . I don't think that it's so important what we're labeled as—everyone is, whether it be directly or indirectly—as long as we don't let our labels "stick". in many ways I consider my ((disability)) a blessing because it makes me who I am. however, i've engaged in many hobbies all of my life and i'll never let it stop me from doing what I want to do in life; i'll always be independent and keep a smile on my face with my head held high. so whether you're on wheels or one of the four-legged clan like me, live your life to the fullest! don't not get out there and do something! keep smiling!

The poster in (15), however, offers a fully politicized message:

- (15) P: In the UK, at least, the disabled peoples' movement has chosen to use the term 'disabled people' as opposed to 'people with disabilities'. The reason for this has nothing to do with anyone's impairment, it is a political statement in reference to the fact that we are disabled by society. For example, I use an electric wheelchair as I am unable to walk (my 'impairment' is ((condition))). However, if I am unable to go to the cinema because there are two steps to the door it is society that is disabling me by not providing a ramp. If there are no steps then I can go to the cinema just like everybody else. If I lived in a world where the entire living environment (i.e. buildings, transportation, etc.) were fully accessible, and people did not discriminate against me in any way then I would not be disabled at all. I would however still be impaired. It is not my impairment that creates the problems, it is the fact that I am disabled.

Both posters here use their life stories in the service of explaining their pride, personal and/or political, in their identity of self-awareness.

The narratives in activist sites, like the narratives in disability organization sites, are success stories, not chaos narratives. Chaos narratives, it turns out, at least in my search of over a hundred sites on the Web, are missing from the discourse of online support groups. They are completely missing from the sites sponsored by disability organizations, especially those devoted to parents of children with disabilities, perhaps because advocacy is the key identity privileged by these sites, and advocacy is intended to keep chaos at bay. They are also missing from activist sites, perhaps because pride in social action is the key identity privileged by these sites, and political realization is intended to explain chaos as oppression. Both types of sites are heavily invested in a particular ideological perspective on success, one popular and one activist, and the postings on both sites remain squarely within these themes.

The closest I could find to chaos narratives in online support groups were in sites devoted to chronic illnesses (it is a controversial question as to whether chronic illnesses and disabilities are quintessentially the same or essentially different; cf. Shaw). In posts to these online support groups, people actually complained of conditions and symptoms that do not get better and explicitly referred at length to their feelings of frustration and even despair. For example, the following post entitled “Too Young to Have ((Condition))” almost seems like an overdetermined chaos narrative:

(16) P: I am 18 years old and was diagnosed last year with ((condition)). I’ve looked back at my symptoms and realize that I have been battling it since I was 12 years old. I had several surgeries for injuries, have gone to innumerable specialists, orthopedic surgeons, acupuncturists, and 3 neurologists. One, has been helpful. The last neurologist I saw diagnosed me. I suffer from chronic back pain with muscle spasms and weakness, joint pain, severe migraines, nervous system disfunctions [sic], ibs ((irritable bowel syndrome)), and just about anything else that goes along with ((condition)). I don’t talk about it much because I’ve always been told, “it’s all in your head”.

I have found that the tricyclic anti-depressants work very well, but I don’t want to rely on pills the rest of my

life. I eat healthy, exercise, and have tried everything I could get my hands on. Most just don't work. I'm tired of this running around, I'm tired of laying awake in bed for hours at a time. I'm just tired of this whole thing. I know I have no more right to complain than the next person, but you have to sometimes, right?

If anyone has suggestions for me, I would love an email.

But there are several subtly positive signs here, too, that lift this narrative out of the chaos category and place it within the chronic disease ideology of learning to live as healthy a life as possible despite the typical medical/social denial of the reality of chronic illness: the user is beginning to realize her chronic disease is a lifelong struggle, in part against negative attitudes (*I have been battling it since I was 12 years old . . . I've always been told, "it's all in your head"*), she is motivated to improve her health (*I don't want to rely on pills the rest of my life*), she has a healthy attitude about complaining (*you have to sometimes*) but not all the time, and she is actively seeking help in this question-narrative (*if anyone has suggestions for me, I would love an email*). Even the most desperate messages on online support groups, then, seem to hold out the possibilities of hope and companionship. Unlike a true chaos narrative like the one cited by Frank and the ones in (6) - (8), ordered discourse has not completely given way to chaos, despair, and apathy.

In sum, then, the online support groups appear to present only narratives of success, from the popular ideology of normalization and hope to the activist model of pride and social action. But the sites do not have chaos narratives that are left to stand as representative of being overwhelmed by disability or disease.

### Comparative Speculations

The obvious question arising from this analysis is why real-life support groups exhibit the full range of disability narratives, including success stories as well as chaos narratives, while online support groups do not. It is possible, of course, that the answer is simply logistical: I may not have found the support groups on the Web where real chaos narratives of disability exist. I certainly cannot claim that I visited every disability support group on the Web; there are surely thousands of them: the *Wall Street Journal* estimated recently that there are more than 15,000 Web sites devoted to

health matters (Carrns), and the media regularly note that health is the single biggest topic on the Internet with millions of Americans visiting health sites each year (Chandler). It is also possible that the answer is a social one: while the white, middle-class mother in (6) might have had access to Internet support groups, the African-American mother in (7) and (8) almost certainly did not, reflecting the socioeconomically skewed distribution of technological resources in American society (Selfe). But I did visit at least one hundred disability support groups and found no chaos narratives, which calls out for at least speculative explanation. I discuss here, then, what I see as two interrelated aspects of real-life and online narratives that underlie the shape and types of narratives: their genres within oral vs. written language, and their socio-cultural frames. I conclude by challenging the received view of the Web as representative of postmodern fragmentation.

One clear difference underlying the narratives in real-life and online support groups is their contrasting forms in oral and written narratives. The narratives in the real-life support group are typical of oral language narratives (Labov; Chafe; Johnstone): they are relatively short; they are structured into idea units of single clauses; and they are highly evaluated, that is, the point of telling the narrative is either explicitly or implicitly conveyed. It is in the evaluation that narratives are thematized, most often in terms of the group, as in the success story narratives in (1) - (5), but sometimes in conflicting terms, as in the chaos narratives of (6) - (8), which thematize frustration and hopelessness. Sometimes the facilitators attempt to appropriate and re-evaluate chaos narratives, as in (6) - (7), but other times the evaluation and thematization of the chaos narratives are left to stand, as in (8). The narratives in online support groups, however, are typical of written language narratives (Chafe): they are much longer than their oral language counterparts (compare the length of (1) and (2) with (9), for instance; they are structured into lengthy sentences; and they are always explicitly thematized within the frame of the site, which is why chaos narratives are not found in sites that promote advocacy and activism.

It is this last point that seems key to me. As Chafe and others point out, written language, even the quickly composed written language of an email post, takes place within a larger context of rhetorical situation. I would argue that any Web site is a rhetorical situation with its own purposes and its established generic structures aimed at accomplishing those purposes. As John Swales notes, "genres are communicative vehicles for the achievement of goals" (46). The genres of a site, then, in direct and indirect ways,



support the purposes of the site, whether that purpose is to support parents in their identities (or potential identities) as advocates or to support individuals in their (potential) identities as activists. The remarkable generic similarity of narratives in online support groups, then, may reflect Carolyn Miller's observations about the power of genre: "What we learn when we learn a genre is not just a pattern of form or even a method of achieving our own ends. We learn, more importantly, what ends we may have" (165). In other words, when users peruse previous narratives in an online support group (and it is usually impossible to post to a group without reading some set of previous posts), they are offered a more or less fixed genre with a more or less fixed set of themes. The prevalence of the success story genre, therefore, reflects the goals of the sites. With the disability sites heavily invested in their goals of advocacy and activism, there is no generic place for chaos narratives to occupy. Further, posters see no examples of generic resistance to the dominant discourse of support group sites (it is possible that resistant posts are eliminated by support group moderators, although most of the support groups I visited appeared to be unmoderated, with free access for posters). Potential posters, then, learn that the ends they can have are already defined by the sites, codified into the genre of success story.

One could argue that the real-life support groups, too, are rhetorical situations with defined purposes and associated genres, and this is absolutely true: facilitators promote the genre of success stories and resist the genre of chaos narratives by actively seeking to reformulate them in terms of the themes and identities of the group. But the rhetorical situation and the genres of the real-life support groups somehow seem more vulnerable to resistance and disruption than online support group sites. The interlocutors can agree or disagree on the purpose of the meeting: when participants agree that the purpose of the meeting is to share information and experiences of advocacy, their narratives model those of the facilitators, as in (3) and (4); when participants see the purpose of the meeting in terms of venting their frustration or focusing attention on their individual plight, chaos narratives emerge and even dominate the discourse of the meeting. The parents in (6) - (8), for example, were remarkably persistent in forwarding their chaos narratives, actively seeking the floor, aggressively piggy-backing their stories onto others', even interrupting the facilitators and ignoring their attempts to re-formulate their narratives or bring the meeting back on track. The oral language situation allowed competing frames for the group—the facilitators' frame of disseminating information and

promoting advocacy in success stories and the resistant participants' frame of venting in chaos narratives. And resistance is rewarded in this oral language situation: sometimes the participants actually managed to change the whole frame of the meeting to their own purposes.

It seems odd, somehow, that this investigation ultimately portrays the real-life, oral language support groups as the less restricted form of discourse, one which encompasses the entire range of disability narratives and thereby has to cope with resistance to its stated aims. It seems counterintuitive that the online, written language support groups are the more restricted form of discourse, one which reflects a restricted range of disability narratives in genres that are apparently strong enough to prohibit contributions which contradict their form and thematization. But this is, perhaps, to ignore the flexibility of exchange in oral language and the strength of genre in written language. Many critics have noted the conservative force of written language (Kaufer and Carley); genre may be one of the ways the Internet has a hidden, coercive nature, a restriction of narrative rather than an expansion. From this perspective, the Internet is not entirely the place of identity creation, free narrative play, and representation of post-modern fragmentation that some critics have claimed it is (Turkle), especially when users come to the net with their real-life identities. Rather, it looks as though real-life is where resistance and the narrativization of fragmentation and chaos can more effectively take place. Discussions of the future of narrative online, then, may have to take more account of its real-life present.

## Notes

<sup>1</sup> The collection of data from support groups was reviewed and approved by the Wayne State University Institutional Review Board (04-25-94(B03)-FB). A letter of support from the sponsoring organization of the support group was filed as part of this protocol. All of the individuals and organizations named in this work remain confidential through the use of pseudonyms: I use the pseudonyms Delores (D) and Jeanne (J) for support group facilitators, and I use the pseudonym P for support group participants.

<sup>2</sup> The collection of data from Internet sites was reviewed and approved by the Wayne State University Institutional Review Board (10-46-99(B03)-ER). All of these organizations as well as the individuals named in this work have been given pseudonyms.

Although it is impossible to absolutely protect the confidentiality of material drawn from the Internet, I have tried to protect confidentiality not only by using pseudonyms but also by not naming any specific disabilities or any sites from which data were drawn.

<sup>3</sup> There are numerous critiques of Frank's work in the literature, especially the critical literature of disability studies. Madonne Miner, for instance, critiques Frank's naiveté in his use of concepts like individual voice: "[W]e might question Frank's seemingly uncritical acceptance of the possibility of speaking one's 'own truth' in one's 'own words' . . . . [And] Frank does not go far enough in pursuing the implications of his own insights, especially with respect to the ways in which [stories occur] within discourses of gender, race, and sexual orientation . . . . Frank falls prey [to] ascribing all representational choices to a subject's experience of illness or disability alone" (284-85). In this work, though, I am not so much interested in critiquing Frank's typology as I am in extending it in a relatively straightforward way to describe and analyze disability narratives.

<sup>4</sup> Special education law in America is both simple and complex. In 1975, the U.S. Congress passed a law known as the Education for Handicapped Children Act (P.L. 94-142), which mandated that children with disabilities receive a "free and appropriate public education" aimed at meeting the unique needs of the child. There is an inherent tension in the application of this law that leads to support groups like the one discussed here, with many of the complexities revolving around the nature of an appropriate education and the funding to achieve it. On the one hand are parents interested in a maximal definition of an appropriate education as the best education, one with all the group-based and individualized services that would meet the needs of their children; on the other side are special education professionals constrained by budgets with severely limited resources. This tension is made manifestly local in the yearly IEPC (Individualized Educational Planning Committee) meetings between parents and special education personnel; the resulting IEP (Individual Educational Plan) assigns the label and placement of each student and details the services the student will receive in the school setting (transportation, therapy, aides, etc.). For an overview of U.S. law as it relates to disability, see Shapiro; for an analysis of the discourse of IEPC meetings, see Mehan, Hertweck, and Mehils.

<sup>5</sup> I have used a broad version of conversation analysis transcription for the oral language excerpts in this work, following a subset of conventions from Atkinson and Heritage (1984: ix-xvi):

• simultaneous utterances		
left hand brackets		[It seem like [We're going to
• incomplete utterances		
word -		s- sat
utterance —		when we were here—
• intonation		
.		falling tone
?		rising tone
,		slightly rising or falling tone/con tinuing intonation
• emphasis		
caps		NOW
• ellipsis/deleted material		
. . .		
• contextual details/pseudonyms		
double parentheses		((district))
• transcriptionist doubt or editing		
single parentheses		(wants) crack(s)

I have used regularized spelling for most words in these excerpts. I have used block form for narratives and other extended utterances because spacing according to utterance or turn would be prohibitively lengthy.

<sup>6</sup> Alert readers will have noticed that the mother delivering the chaos narratives in (7) and (8) is the same mother that delivered a success narrative in (3). Devon's mother offered the success narrative in (3) at the beginning of the meeting, when her narratives were closely tied to the themes and identities of the group. In the second part of the meeting, though, Devon's mother's narrative escalation moved towards chaos narratives as she abandoned any attempt to thematize her stories within the discourse of the group. I have described her narrative escalation more fully elsewhere (Barton, "Sanctioned").

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