

Culturally Available Narratives and Second Storying in Disability Narratives

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In an essay in the *New Yorker*, novelist Jonathan Franzen describes the current proliferation of first person accounts as a desperate attempt to traverse the sometimes self-imposed, sometimes stigma-imposed gulf between oneself and others. His discussion challenges what has become a premise in oral history and life history research, the idea that recognizing oneself in a shared narrative can mitigate the experience of feeling that one is alone, the only one who has had or who knows some experience.

In my work, although I have argued against the too-easy and often erroneous idea that stories make meaning out of the chaos of experience—the fact is, sometimes they do, and sometimes they don't—I still hold to the claim that the proliferation of personal narrative is part of the fundamental process of recognition that is central to building community and to countering stereotypes and prejudices (Shuman, 2005). Today I focus on mutually constituted culturally available narratives and counter narratives.

Although our concern at this conference is with first person *writing*, rather than speaking, I think it will be useful to draw on some conversational first person research to suggest that the concept of second storying offers one way to understand the relationship between culturally available narratives and counter narratives. In conversation, shared narrative can be marked by “that happened to me, too,” or “I know what you mean.” These frames,“ although seemingly a sign of

recognition, have more to do with the interaction among the participants than with knowledge about others' experiences. I will argue that, more generally, the concept of availability is intertextual and describes more about the position and alignment of the participants than about the knowledge they have or don't have about each other. Saying that a narrative is available does not mean that narrators consciously or strategically assess a corpus to find a suitable narrative. Availability points in seemingly different directions, to the availability of shared communicative resources and to familiar scripts that explain life experiences, but, as I'll discuss in a moment, they both involve a temporal disjuncture that is at the core of creating narrative meaning. Available narratives come to consciousness most often when someone rejects a familiar script or expresses offense at a violation of the usually unstated rules for who can say what to whom and when. Narrative is one way of attempting to make sense of traumatic situations that completely disrupt ordinary life, but once disrupted, and it is always disrupted, attaining the ordinary is an inevitably unfinished project.

Today, I will consider three dimensions of the concept of available narratives. First, I will address how co-participants position themselves in relation to each other as part of producing mutual understanding through what are called second stories, or stories that say, "that happened to me, too." Second, the examples I will discuss today, of parents' stories about children with disabilities, raise questions about the tellability of stories and what is sayable and unsayable. Third, as a conclusion, I'll address questions of intertextuality, scripting, dialogic narration, and narrative circulation as part of the larger problem of available narrative. Borrowing

Judith Butler's term, I want to "work the gap" between the multiple available narratives—the idea of available narratives is a seamless point of connection, but to the extent that that is accomplished, it's an effort to obscure the inevitable gaps, that occur at all levels, not only between my understanding of your experience, but also, temporally, for example, in a person's retrospective account of what happened and what should happen next. It's fundamentally an intertextual gap.

I begin with Harvey Sacks observations that second storying, saying something like "that happened to me too," is not so much a shared topic but a shared interaction (768). Second storying, which has its equivalents in writing, is an example of intertextuality. In conversation, it is a way for co-participants to orient toward each other; in both writing and speaking, it orients, or aligns texts to each other. The particular phrase, "that happened to me too" is what Erving Goffman later described as a frame, but Sacks takes his discussion in a different direction. Quoting Freida Fromm-Reichmann's *Principles of Intensive Psychotherapy*, Sacks points out that the second storyteller has been reminded of a story by the first. (768). It is offered as if prompted, framed as a spontaneous remembering. And this is where Sacks makes a particularly interesting observation.¹ He says that we aren't reminded by a particular character or incident. Instead, he writes, "What seems to happen is that the character that the teller was in the story they tell you, is the character that you turn out to be in the story that you tell them." In the second story, the teller plays "an equivalent role to the storyteller" in the first story (769).

This may look like a very small point, but it leads to a larger point about how storytelling about personal experience can produce mutual understanding. In

Sacks' example, the first teller describes seeing a car accident. The second teller describes experiencing the same sort of thing the first teller described. By saying "that happened to me, too," the second story offers confirmation or agreement with the first, for example to signal that the teller did the right thing in a difficult circumstance, or that the listener understands what the first person suffered. In other words, second storying is a way of demonstrating understanding. Sacks writes, "It's not unique, you're not alone, you're not crazy to have done it, etc. etc. i.e. you look at the world right" (771).ⁱⁱ

For the past decade, I've been working on the role of available narrative in political asylum hearings, where asylum applicants often fail to comply with the implicit expectations of the hearing officers. Like Hurwitz' discussion yesterday about documenting health practices, the asylum system has multiple different documentary processes, each with its own unstated narrative requirements. Today I turn to newer research, on stories told by parents of children with disabilities. This project is similarly about how personal narratives are constrained by different documentary processes. Parents of children with disabilities, like many people narrating about trauma and illness (which are, of course, different) often describe the experience of being unmoored, on unfamiliar ground. They don't say so in so many words, but they describe a connection between the loss of predictability and the loss of explanation. They (and I include myself here) are describing no longer having the moment before, as in the moment between the time the phone rings and you answer it, or the moment in between the lightening and the thunder, or between seeing someone across the street and recognizing that it's someone you

know. (Ann Carson, "Gnostism" *New Yorker* 3/24/2003 pp 56-57 "in between when you hear the phone and when you get it, all palpable explanations of why it rang and what to do" p 56)

Narrative is, in part, about this connection between predictability and explanation. Narrative form and genre guides us to at least recognize that the characters are about to choose one fork in the path rather than another, if not actually predict which path that will be. And those connecting choices often are driven by or add up to an explanation that helps us to understand how things came to be as they are.

Parents' stories about their children with disabilities often stand against, in contradiction to, in defiance of, or as an alternative to the many other narratives, especially those imagined narratives that the parents may have once believed, before they became the parent of a child with a disability. First person writing often serves this role, a testimony to a personal truth that needs to be told to set the record straight or to resist a commonly held misperception. In the case of narratives about being the parent of a child with a disability, these stories often carry some insistence. Like other situations, especially anything related to illness or impairment, disability is narrated in euphemism;ⁱⁱⁱ much is unsayable, or what is said doesn't always apply.

Parents of children with disabilities often describe needing to rethink the script of their and their child's lives.^{iv} Children with disabilities sometimes don't achieve the same milestones as other children; indeed, this is one of the things that marks them as having a disability. We could say that having a disability means

having a different plot, a different narrative. The medical term for the narrative of disability or illness is a prognosis, a set of expectations and limitations. Gail Landsman writes, “By leaving a prognosis undetermined, the stories allow hope for a future without disability” (2009: 118).

Here I am focusing not on the life narratives, the exquisitely formed stories that make sense of even the most chaotic, incomprehensible, unpredictable parts of a life that doesn't fit the usual script of being a parent (which of course doesn't ever match reality), but the snippets. It's the snippets that both capture the sense of finding oneself in events one never imagined and that people may not want to hear and that sometimes make their way into inspirational stories that get passed from one person to another, as inspirations that remind people to count their blessings or to strive harder to overcome their difficulties.

It's these snippets that motivate me to write about being the parent of a child with disabilities, because the inspirational ones, though they move me, inevitably make me mad, angry on the part of the person whose story has been robbed, as if the life itself only counts when it serves as inspiration.

One of the available narratives is the self-sacrificing mother; Skinner and Bailey, p 487 report that this theme was found in 73% of their interviews. For example:

For me, that was an experience which forced me to mature **{madurar a la cafiona}**. I had to give up who I was to be able to become my son's mother.... I forgot everything. And I dedicated

myself to finding all that would benefit
my son, so that in the future I would be able to
say to myself that at least I did something. He
didn't recover his sight, but at least I did something
so that he could begin to act more or less
like a normal child. (Skinner and Bailey 1999: 486)

Many narratives have this structure, beginning with the discovery of the disability, the acknowledgment of the fact that things will never be as they were, and then, importantly, forecasting a future.

A second available narrative refers to the idea that God chose the parent to have this child. In some cases, this narrative is posed as the counter-narrative to the idea that a parent with a child with a disability is being punished for something they have done. For example:

I think that I was chosen to have a child like this. For example, there is a woman I met who was very materialistic and vain. She was Puerto Rican. She once said something about my child that made me think she couldn't handle (no podía bregar) a situation like this. That was when I realized that God chooses people because I don't believe He could send a child like this to a person like that, rather to someone who can give herself (alguien que se entregue) like I have done" (Skinner and Bailey, 1999: 487).

This narrative more directly references what is often an unsaid alternative story. The narrator positions her own (second) story against that of the Puerto Rican woman who couldn't handle it.

A mother of two children with intellectual disabilities offers the same second story.

“Silly people expect me all the time to do all the right things, as though they were saying, ‘All right, now, be God-like!’” (Murphy, 1981: 57).

In all three of the stories, the parent takes up a character defined for her by someone else. The gap is produced by the contrast of these characters. This sort of available narrative is often explained by the obviously relevant cultural, and especially religious discourses, but I think we miss understanding how available narratives work when we point to contextual difference rather than the intertextual gaps as the source of the problem of the available narrative.

Available narratives refer to a collective and accepted discourse, what Judith Butler describes, referring to Theodor Adorno, as a collective ethos. Butler begins her book *Giving an Account of Oneself* with Adorno’s argument that moral questions only arise when the collective ethos has failed (2005: 3) and, she insists, this failure is not something to mourn. “The collective ethos is invariably a conservative one, which postulates a false unity that attempts to suppress the difficulty and discontinuity existing within any contemporary ethos” (2005:4). It is the appearance of collectivity.

Following this argument, we could say that use of available narratives confirms the illusion of collectivity and perhaps suppresses discontinuities and difficulties. Importantly, for my discussion, Butler describes this as an anachronism, not something living in the past, but instead refusing “to become past” (2005:5). This temporal disjuncture is crucial for understanding how narrative projects into a future, claims past understandings as continually valid, and participates in and

perhaps obscures that moment that I described as the in between, between the phone ringing and answering it.

Harvey Sacks accounts for this temporal disjuncture at the level of narrative interaction. He describes availability as imagined, hoped for. He gives several examples of people in terrible circumstances imagining telling about it later, in fact, imagining surviving it to be able to tell it (1992: 218, 780). He writes, "In living through, e.g., an experience of pain, one can, by virtue of attending its tellability, make it somehow more bearable, in that, in viewing the occasion of its tellability one can visualize one's survival at least until then" (1992: 780). He continues by pointing out that the importance of this availability is independent "of whether one, oneself, will be available to tell it." (1992: 780).

Availability, then, is a temporality problem. It's not only the problem of needing to remap a past leading to an unexpected future, as Arthur Frank describes in his discussion of illness narratives (1995: 55). Granted, one of the problems faced by parents of children with disabilities is that there are no scripts to describe their experiences, and at the same time, others, especially professionals, are scripting their lives for them. For example, in their reports, professionals write,

They're not being realistic';

`They won't accept the child'; `They're shopping around,

looking for someone who'll say there's nothing wrong'.^v

Tellability....A parent who decided to place her daughter in an institution several decades ago wrote:

My daughter is never going to be anything but a headache to me or anyone

else. She has no future,. And I don't plan to spend the rest of my life being a slave, twenty-four hours a day taking care of her and alone at that—I get no help from him—he goes around the world not knowing we exist. Well, now it's time for me to get something out of life. I'm going to start to live again—for myself.

And along the same lines, another parent said,

I sometimes think of myself as a robot: 'the care-taker.' ...But still, deep inside me, a voice—the old voice I listened to for years—comes back to haunt me, and twinges of guilt and duty and rightness crop up within me...I wonder if these feelings and all the hopes I have, my own personal longings, I wonder if they make me an unnatural parent. (Murphy, 1981: 46).

The first two examples, first of a self-sacrificing mother and second of a mother who feels divinely chosen for her task, stand against the second two examples, in which being a mother and having a self are described as incompatible.

In his marvelous memoir/autobiography about being the parent of a child with Down Syndrome, Michael Berube invokes all of the above narratives and more to tell his story of being a parent who is constantly surprised by what his son Jaime can and cannot do. He writes against the culturally available narratives about children with Down Syndrome and their parents, and importantly, he cannot forget them. Counter narratives, as Mark Freeman points out, are not about forgetting. Instead, memory and forgetting are in a dialectical relationship in which an excess of memory makes any particular account either sustainable or adequate. Parents of children with disabilities often describe themselves, as do the parents I quoted, as

not having chosen their children. Given this lack of choice, many describe themselves as making choices, whether the choice to live for themselves, for their children, or, in Berube's case, for a larger cause of disability rights. But we might be confused by this narrative move of choice if we fail to see it as a second story. Observing the intertextuality of counter-narratives as second stories to culturally available narratives opens up the gap that is obscured if we see the second narrative as only a rejection of the first. Instead, both are implicated in the narrator's memory. In Mark Freeman's terms, they expose a surplus that exists within historical consciousness (2002: 204). The category disability only exists as a second story to this historical consciousness, expressed in countless narratives of ability.

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Notes

ⁱ See Arthur Frank's discussion of Roger Schank who says "We need to tell someone else a story that describes our experience because the process of creating a story also *creates the memory structure* that will contain the gist of the story for the rest of our lives. Talking is remembering" (1995: 61).

ⁱⁱ See also Arthur Frank: "Stories have to *repair* the damage that illness has done to the ill person's sense of where she is in life, and where she may be going. Stories are a way of redrawing maps and finding new destinations" (1995: 53)

ⁱⁱⁱ Landsman reports the following: “When asked to define the term [developmental disability], one doctor at the Newborn Followup Program responded, ‘It means your child is mentally retarded but I don’t have the courage to tell you’” (2009: 107).

^{iv} See Landsman on the ‘trauma of dashed expectations’ (1998: 76).

^v “When professionals interpret parents’ words and behaviours as denying reality, rather than demonstrating the ideals of ‘acceptance’ and ‘being realistic’, the parents may be viewed as dysfunctional.” (Kearney, 2001: 583)