



'Trial by fire': forms of impairment disclosure and implications for disability identity

Heather D. Evans

To cite this article: Heather D. Evans (2019) 'Trial by fire': forms of impairment disclosure and implications for disability identity, *Disability & Society*, 34:5, 726-746, DOI: [10.1080/09687599.2019.1580187](https://doi.org/10.1080/09687599.2019.1580187)

To link to this article: <https://doi.org/10.1080/09687599.2019.1580187>



Published online: 12 Mar 2019.



Submit your article to this journal [↗](#)



Article views: 311




View related articles [↗](#)



View Crossmark data [↗](#)



'Trial by fire': forms of impairment disclosure and implications for disability identity

Heather D. Evans 

Department of Sociology, University of Washington, Seattle, WA, USA

ABSTRACT

This article examines the ways in which people living with non-apparent impairments, sometimes called 'invisible disabilities,' choose to disclose their impairments to friends, colleagues, and supervisors. Drawing on life-history narratives conducted with 12 men and women who acquired non-apparent impairment through accident, injury, or illness, this analysis demonstrates that people who have acquired non-apparent impairment use three primary forms of disclosure – confessional, pragmatic, and validating – serving as mechanisms by which individuals internalize the stigma associated with disability, pragmatically acquire accommodations, or resist and challenge ableist views. This analysis shows the ways that disclosure more broadly, and these forms specifically, play important roles in developing and negotiating disability identity.

ARTICLE HISTORY

Received 21 June 2018

Accepted 3 February 2019

KEYWORDS

invisible disability;
disclosure; non-apparent
impairment; disability
identity; life-history
narratives

Points of interest

- People with non-apparent impairments or 'invisible disabilities' have the widest range of options available to them about whether to disclose, what to disclose, and to whom to disclose impairment information.
- This analysis shows that the way a person chooses to disclose impairment information plays an important role in shaping one's personal identity in relationship to disability.
- In contrast to disclosing facts as part of obtaining necessary accommodations, sharing impairment information in order to apologize for poor performance or ask for a favor reinforces feelings of shame about being disabled.
- Individuals with non-apparent impairments or 'invisible disabilities' sometimes disclose impairment information primarily in order to gauge other's reactions and weed out people who do not share their values.

Introduction

I can only articulate it with others in my TBI [traumatic brain injury] community because only they will understand what the everyday brokenness feels like. And it comes down to – one of the biggest things – how do you explain this to someone you're gonna date? How do you explain it to an employer? How do you explain it to – or when do you disclose and when don't you? And nobody gives you lessons on this. And it's like trial by fire, and you wanna get angry. For crying out loud, I cannot be the only person. (Molly, living with traumatic brain injury)

This article examines the ways in which people living with non-apparent impairments, sometimes called 'invisible disabilities,' choose to disclose impairment information to friends, colleagues, and supervisors. Drawing on data collected as biographies of 12 men and women who acquired non-apparent impairment through injury or illness, this analysis identifies three primary forms of disclosure – confessional, pragmatic, and validating – that serve as mechanisms by which individuals internalize the stigma associated with disability, pragmatically acquire accommodations, or resist and challenge ableist views. Understanding primary forms of disability disclosure illuminates the ways in which the decision to share impairment information serves as a key mechanism for managing one's identity in relation to disability.

Findings show that multiple disclosure strategies are often employed by the same individual in different social contexts. Thus, these three forms of disclosure reveal different approaches to not only managing disability identity but integrating that identity into a broader sense of self. Confessional forms of disclosure can bolster internalized notions of disability stigma, revealing impairment in order to justify asking for services or to apologize for perceived deficiency in one's performance. Pragmatic disclosure conveys impairment information in very practical terms, using disclosure to enlist others in reducing barriers to productivity in built and social environments. Validating forms of disclosure assert disability as a legitimate, integrated identity. By aligning one's personal experiences with the barriers faced by disabled people more broadly, validating disclosure signals a political identity that resists systems of oppression against a shared, minority status. Different forms of disclosure impact individuals' self-perceptions and signal to others political alliances, rights awareness, or an apolitical view of disability. This analysis shows the ways that disclosure broadly, and these forms specifically, play important roles in negotiating and communicating disability identity.

Background

Disability Studies scholars have thoroughly documented how non-typical ways of physically, emotionally, and cognitively functioning have been

conflated with 'disability' – the latter being a socially constructed status that changes across cultural, economic, political, and historical contexts (Shapiro 1994; Linton 1998; Longmore and Umansky 2001; Heyer 2002; Heyer 2007; Schweik 2009). During the latter half of the twentieth century, disability rights advocates offered a sustained critique of the medical model of disability which pathologizes difference, offering instead a social model of disability that emphasizes barriers to participation in society for people with impairments. The social model squarely situates disability in the interactions between an individual's way of functioning and the social or built environment (Linton 1998; Longmore and Umansky 2001; Switzer 2003; Barnes and Mercer 2003; Shakespeare 2013.)

Framing disability as an interaction between an individual and their environment heightens the role stigma plays in shaping one's identity. Erving Goffman famously defined this term as "an attribute that is deeply discrediting" (1963, 3). Goffman also argued that to understand stigma we need "a language of relationships, not attributes," underscoring the interactionist nature of social stigma (1963, 3). Stigma has also been widely studied by health researchers and social scientists exploring illness (Zola 1982; Frank 1991, 1995; Chaudoir and Quinn 2010). Psychologists have demonstrated correlation between disclosure of a stigmatized identity and psychological health (Chaudoir and Quinn 2010), finding that positive first-time disclosures are associated with a variety of long-term psychological benefits (while negative experiences result in long-term detriments).

More recently, Disability Studies scholars have explored disclosure in a variety of contexts. Numerous studies examine the ways in which disabled people share impairment information in online environments, examining the role of disclosure, for example, in building networks through social media (Coopman 2000; Kaye 2000; Medjesky 2008; Chatterjee 2010; Furr, Carreiro, and McArthur 2016) or participating in online dating platforms (Bowker and Tuffin 2010; Saltes 2012). Analyzing online disclosure decisions among people with physical impairments, Furr, Carreiro, and McArthur (2016) identified three categories comprising "open, secure and limited" disclosure, describing the amount of information shared to different online groups. This article adds to this literature by also examining decision-making among a population who has a wide range of choices about what to disclose. Examining in-person disclosure by such a population illuminates the ways in which social context shapes disclosure decisions in the moment, revealing the complexities of the social model in action.

Studies analyzing in-person disclosure of neurodiversity, mental disability, or madness provide valuable insight into the interactive nature of identity-building through disclosure of non-apparent differences (Irvine 2011; Pilling 2012; Price et al., 2017; Sarrett 2017). Often, these forms of disclosure are

analogized to ‘coming out’ experiences in the LGBTQ community (Shakespeare 1996; Cameron and Swain 1999; Corrigan and Matthews 2003; Pilling 2012) due to the lack of visibility of sexual identity (see Samuels [2003] for a critique of and discussion on the limitations of this analogy). This literature, however, focuses on the ways in which the reactions of discloseses (people to whom a person discloses) shape disability identity. The research presented here adds an important dimension to this body of work by examining the role of disclosure decision-making alone in deepening or distancing oneself from disability identity.

As previous research has demonstrated, decisions about when and to whom to disclose impairment information are pivotal in disability identity management. Studying people with non-apparent impairments provides a unique window into stigma and identity management. Stigma management centers on individuals’ ability to control their ‘discredited identities,’ meaning, as Goffman put it, “visibility is crucial” (1963, 48). Individuals with non-observable differences in functioning cannot rely on others to infer disability, but must instead engage in conscious decisions to pass as non-disabled, downplay their impairments, or fully disclose (Goffman 1963; Renfrow 2004; Yoshino 2006; Evans 2017). Thus, individuals with invisible impairments that have been acquired are a particularly salient population among which to examine the impact of disclosure decisions, as they have the widest possible range of options open to them for managing stigma and negotiating disability identity.

Research process

These data reflect life-history narratives from 12 individuals living in the Pacific Northwest with non-apparent impairments resulting from illness or injury. Here, I use the term ‘life-history narrative’ to mean a narrative account about a person’s life (Bathmaker and Harnett 2010; Chase 2005; Laslett 1999; Plummer 2001) before and after acquiring a non-apparent impairment. I solicited life-history information through multiple interview sessions with each participant, orienting our discussions around important moments of disclosure, asking them to discuss and reflect upon what Robert Zussman (1996) calls “autobiographical occasions.”

An autobiographical occasion is a time when a person is called upon to narrate – that is, organize, interpret, and present – a slice of their life. Social scientists regard autobiographical occasions as moments when individuals must disclose personal information to institutional representatives (e.g., case workers, police officers, doctors, researchers) or to intimates when prompted by a key event (Zussman 1996, 2000; Leonard and Ellen 2007). When autobiographical occasions are contextualized in the analysis of a particular

group, these moments provide insight into underlying social processes impacting that population. Robert Zussman (1996, 143) argues that biographical tales are “made distinctively sociological by their placement in an analysis of a particular social situation or social type” and that through situating personal narratives into their social, historical, and political context we can gain insight into the complex relationship between society and the self.

These data were analyzed using a modified grounded theory approach (Bowen 2006; Charmaz 1995; Cortazzi 2001). I engaged in data collection, coding, and analysis in tandem; after each interview session, audio recordings were transcribed and coded. Once all interview sessions were completed with each individual, I coded and conducted in-case analysis of each biography, and then across-case analysis when all life histories were collected. Identifying recurring codes helped unpack dominant themes and develop the analytic categories presented here (Riessman 1993; Tierney 2000).

My positionality impacted my approach to study design, including both data analysis and collection. I am a disabled, white, cisgender woman and thus share many axes of identity with my participants. As a person with non-apparent impairments, my perspective is that of an insider among this population. Having lived with a degenerative disease for over 20 years, I have cultivated relationships with others in similar situations. Three study participants were referred to me through these contacts.

My positionality as a disabled researcher influenced my decision to incorporate the three principles of ‘emancipatory research’ identified by Mike Oliver (1992): reciprocity, gain, and empowerment. I was reciprocally open with participants about my own impairments and answered as many questions as each participant chose to ask throughout the research process. I conducted life-history narratives through multiple interview sessions with each participant, transcribing and completing a first pass of coding prior to the next session. This allowed me and the participant to review our last session together, correct any misinterpretations, and follow up on key issues. Participants thus gained what Amy Petersen describes as the “the power and importance of telling one’s story for *oneself*” (2011, 300; original emphasis). In addition to handing over more control to participants, this approach accommodated my frequent bouts of fatigue and opened up conversations with each respondent about ways to best accommodate their own needs. All but three participants concluded their interviews by sharing that narrating their life story had been profoundly instructive, if not beneficial, and two requested their completed transcripts for personal use.

This analysis reflects a largely white, relatively educated experience of acquired impairment; only one participant in the study is a person of color. Three men and nine women participated. The youngest participant was 29 years old at the time of interview; the oldest was 54 years old. The time

since diagnosis or injury also varied notably: the most recent diagnosis occurred within 1.5 years of the interview; the oldest was 18 years. All participants had attained at least some college education: three participants had or were in the process of acquiring a doctoral degree, four had master's degrees, and two had completed bachelor's degrees. Seven participants were working full time at the time of interview, one was working part time, and four were unemployed and not looking for work.

Although all participants have some level of higher education, a wide range of occupation and income levels are represented (and do not map neatly onto education level). The participants include a person who is homeless, teachers, biomedical researchers, security guards, students, healthcare workers, and government employees. Participants reported impairments associated with car accidents, head trauma resulting from accidental injury or violent assault, multiple sclerosis (MS), Crohn's disease, chronic Lyme disease, macular degeneration, cancer, and digestive disorders. Three individuals were recruited through personal referral, six responded to flyers posted at neighborhood clinics or chronic illness specialty clinics, and three were recruited through announcements posted at food banks. The names of participants have been replaced with pseudonyms to protect their privacy.

This article focuses on forms of disclosure practiced by participants, not on others' reactions to disclosure. It is important to note that all participants, without exception, provided stories and examples of negative reactions to impairment disclosure, whether the impairment was their own or that of others. Many participants articulated ways in which stigma around disability in the workplace and in American society negatively affects individuals who identify themselves as such. This analysis is not intended in any way to discount the very real, negative disclosure experiences nor pressures to minimize impairment that participants endured.

Each case presented here involves impairments that may be temporary and/or non-apparent. As a result, these individuals have the widest range of options available to them of fully disclosing, passing as non-impaired, or attempting to cover or minimize their impairment (Goffman 1963; Yoshino 2006; Brune and Wilson 2013; Evans 2017). This decision-making process both reflects and shapes individual understandings of disability identity.

Findings

Disclosure decisions made by people living with acquired, non-apparent impairments fall into three broad categories: confessional, pragmatic, or validating. Deciding whether – or to what degree – to disclose impairment is a decision to expose oneself to the scrutiny and/or judgment of others based on a stigmatized status. Understanding disability as a social construction

means that decisions to disclose are in and of themselves constitutive moments of identity formation. People who must articulate to others that they are experiencing impairment often employ a confessional approach to telling friends and colleagues about their hidden impairment, using disclosure to explain a perceived deficiency in their performance or to justify asking for something out of the ordinary. In other circumstances, people convey impairment information in very pragmatic terms, using disclosure to enlist others in navigating built and social environments by communicating the technical specifications for maximum productivity (or less hindered activity). Finally, people with non-apparent impairments may use disclosure to validate their disability identity, signaling a political identity that calls out systems of oppression against a shared, marginalized status. Because people who have acquired non-apparent impairment must deliberately communicate their circumstances to others, the form of disclosure they select impacts the way they see themselves in relation to disability.

Confessional disclosure

All participants described incidents of disclosure in which they conveyed impairment information in order to justify asking for help or explain what they perceived as poor performance stemming from impairment. I refer to this form of disclosure as 'confessional' because the language used to describe these occasions was laced with phrases such as "fessing up," "shameful admission," and "keeping secrets," denoting feelings of guilt or shame associated with impairment. For example, Lionel described situations in which his low vision prevents him from helping students with computer work, prompting him to explain his sight impairment:

I may need to lean close or I might not be able to help at all, which is what I try to tell them. ... I want to help, but I'm not able to and it's always a reluctant, it's like an admission of guilt or something. Shameful, like a shameful admission. (Lionel)

Other participants described "being caught" and disclosing. Dahlia related disclosing to her supervisor at work during a flare-up of her digestive disorder after a few days of "coming to work and just being miserable." She explained: "There's been a few instances during this time period where I was just, like, not able to stop crying. So he had caught me in the elevator. Like, I just couldn't hold it in and ... I disclosed it then."

Participants also described disclosing information about impairment in order to justify asking for help. There is a distinction between sharing information necessary to obtain assistance or accommodation (for functional or practical purposes) and disclosing in order to justify asking for help. On the surface this distinction may seem semantic, but the difference in disclosure revealed participants' differing views of themselves, at that moment.

Providing information to obtain an accommodation reflects an assertion of rights, akin to non-disabled employees requesting workplace technologies or arrangements that boost their productivity. By contrast, confessing the need for accommodation frames disclosure as a process of revealing a personal failing that needs to be explained, and any related requests, justified.

When participants framed disclosure decisions in terms of “asking for a favor,” disclosure conversations reflected a confessional tone. Dahlia listed multiple examples where disclosure about her food allergies made her “feel guilty” about asserting her needs in social situations. She explained:

I don't know. Just in the beginning, when I was first diagnosed, just the social aspect of it, and I was, like, 'Oh, god. I'm asking somebody to do something for me.' You know, just that whole thing of, like, you know, I'm usually giving to other people. I'll usually cater to them. So this was me having a need that I right away had to ask from other people. So that was kind of a little nerve-wracking ... (Dahlia)

To be clear, in this context, Dahlia's request for “somebody to do something for me” consists of asking restaurant waiters to verify all items in certain food dishes and asking her colleagues to include food she can eat during weekly pizza parties. Although Dahlia says she has become more comfortable with disclosing over time, she stated that disclosing to new social acquaintances often still makes her feel guilty.

Decisions not to disclose can also reflect a confessional approach. Tammy, explaining why she did not disclose having Crohn's disease at a job, stated:

It wasn't really necessary and ... it's kind of embarrassing. And I didn't like, it impacted ... like, that was the thing, I was finding ways to create the flexibility so I didn't need to ask them to do something for me. (Tammy)

Tammy was more comfortable “finding ways to create flexibility” than disclosing an “embarrassing” impairment, so chose not to disclose to her colleagues until she needed to “ask them to do something” for her. Lionel describes asking for assistance due to his visual condition as “hard for [him].” He describes the tension between revealing his impairment and the benefit from disclosing:

Well I have to ask people at a restaurant for a written menu, I have done that but it's hard for me. I've asked people at the grocery store: 'could you read the nutrition information off of this for me?' because it's really small text. I've done that, it's hard for me to do but at the same time it's easy to do and people are generally willing to help. And usually, it's a stranger, so it doesn't really matter if they do think less of me. It's a weird conversation in my mind. I care about it but I don't care about it because this is a stranger to me. So I have asked for help plenty, it's just that overall, I tend not to. I'm more comfortable just not doing it. ... I am always pleased to be helped. Like having someone read something to me, I'm better off having done that, but I don't really want it. It's hard to put into

words exactly. It's like different parts of me, different parts of my brain fighting. (Lionel)

Nina, Sally, Molly, and Diego also reported inner tensions between asking for help and choosing not to divulge impairment information. Decisions to not disclose were also made for pragmatic reasons, but when participants described guilt, embarrassment, or shame as preventing them from disclosing, this decision-making process is embedded in the confessional approach.

Participants also employed disclosure in order to justify or explain what they believed to be poor performance due to impairment. Indeed, several participants claimed to have "learned lessons" from waiting to disclose until their work or relationships had been impacted by a period of exacerbated impairment. For many participants, the lessons learned led to a more pragmatic approach to disclosure in later situations. Nonetheless, participants reported disclosure conversations prompted by their attempts to apologize for or explain a change in their productivity. Dahlia explained that while she had already disclosed to her supervisor at work, she did not disclose to the manager until she started having to take time off and worried that people would "start noticing.": Dahlia explained:

I tried to just be as strong as I could for as long as I could while I was getting sick, and then I did kinda sit down with my manager ... and just say, 'Hey, I'm having this issue, and, you know, I apologize if I'm not doing as well, but here's what's going on.' (Dahlia)

Jane, living with chronic Lyme disease, experiences intermittent periods of (literally) blinding migraines, severe joint pain, nausea, and cognitive disruption. She reports growing more comfortable over the last 10 years in disclosing to friends, but Jane draws a bright line between disclosing to intimates and sharing her impairments with employers:

It's different with employers. It always worries me with employers that I might be seen as an unfit person in a job role and that really scares me. It can like get in the way of me holding a job or get in the way people hiring me. (Jane)

Until relatively recently, Jane told coworkers and employers that she has "headaches" that sometimes cause impairment:

I told my boss[es] that I get headaches every now and then and that ... Like sometimes I wear sunglasses indoors because sometimes my eyes will hurt because of the light. And that's kind of awkward. Like I tell people: I am wearing sunglasses inside, I am not a rock star, I have light sensitivity issues ... And so I just kind of chalk it off as other stuff. Stuff that other people could relate to, you know. People can relate to having really bad headaches. (Jane)

Rather than disclose a chronic illness that remains a controversial diagnosis within the medical community, Jane communicates her periods of exacerbations using "stuff that other people can relate to" such as headaches.

However, a prolonged period of exacerbation, combined with a set of coworkers that appeared to be genuinely “supportive” of each other, prompted Jane to disclose to her employer nine months into her current job. In response to being asked what prompted her decision to disclose, she stated:

Not wanting to lose my job. [Laughs.] I’m always scared that I will lose my job because of episodes of this. But I have been having a few more – it kind of comes and goes in waves, like sometimes I do really well for a while and I’m fine and then at times I will do really bad for a while and sometimes I just do bad occasionally and ... That’s pretty much what it’s been, it’s been either a mixture of doing not so great occasionally and then I would just call in sick. But then there was a good week there where I was not doing good at all and I was pretty much having to call in sick for a week kind of thing. And I was just like, I am going to get fired because I can’t keep calling in sick and there is no like proof of me being sick... So I told her: I feel really awkward talking about this, talking about this makes me feel vulnerable, I generally don’t talk about this with people because I don’t want you to think that I’m not good at what I do, you know ... This job means a lot to me and I want to keep this job but – I have Lyme disease. (Jane)

Jane reported that her employer responded positively to her disclosure and the conversation resulted in a discussion of accommodations that could be arranged during periods of exacerbation. For Jane, the decision to disclose was rewarded with support and perhaps even improvement in her working conditions. However, the decision was also fraught with fear and prompted by the need to explain her absences at work.

Jake also decided to disclose to a supervisor after a period of blindness in one eye (among other symptoms) associated with MS. He described the experience of waiting to disclose until he was well into the throes of an exacerbation as teaching him a “valuable lesson” about communicating to others when his work productivity fluctuated due to impairment. He described the disclosure incident:

Jake: Umm. [Short pause.] She looked at me kind of buggy eyed for a second. Like, ‘you’re shitting me’ is the way I interpreted the look. Because I was a bit of a wreck at the time.

Heather: What about your side of the conversation, do you recall roughly what you said?

Jake: What did I say to her ... ? Essentially, ‘I have MS, I’ve been blind, um, sorry, I should’ve told you before. In some way, this probably explains my performance in the lab, but probably not entirely. And, oops. I should have handled that differently and so ...’ Revert to buggy eyes.

Jake described this incident as a “disclosure fail” and his experience with this supervisor led him to eventually develop a different strategy for impairment disclosure on the job, a strategy that is more proactive and pragmatic.

Pragmatic disclosure

Pragmatic disclosure encompasses decision-making based on clarifying ways in which the environment could be adjusted to promote one's productivity. Ironically, barriers in the built environment are often the easiest to identify and remediate. Adjusting social environments in ways that reduce barriers can be more difficult; thus, pragmatic disclosure also plays a key role in managing others' expectations, particularly during periods of heightened impairment.

For those in work environments that already have some flexibility, a pragmatic approach to disclosure allows people to take full advantage of existing norms. Tammy expressed relief at finding a job in a place that had set norms allowing employees to flex their time. This environment made her feel comfortable disclosing to her boss that she had a chronic illness and she sometimes needed time off for appointments. Importantly, having flex-time made her feel comfortable sharing her reasons for leaving the office rather than justifying asking for time off. Tammy explained:

So in my early stages with the department that I am in now, they knew that I had Crohn's, I had had some quiet conversation with folks. ... I told my supervisor that I had to have this little thing done and he was like: okay sure, just make sure you are covered. And that was really nice. Like I said, there were signals that this was a more flexible workspace. (Tammy)

Molly also described the benefit of disclosing in order to provide collaborators with context when working as a team. Molly described a recent planning session:

And I have taken it to a second step of informing them of things they don't need to know about, but so that they have the context so that they can maybe take a pause and say, 'Wait a second. When we're creating this plan, does this actually work for you?' (Molly)

Using a pragmatic approach to impairment disclosure clearly communicates an individual's needs in the workplace. When living with impairments that may intensify episodically, communicating specific accommodation needs beforehand can be challenging; pragmatic disclosure thus plays an important role in laying the groundwork for future accommodation requests and helps set others' expectations.

All of the participants working full-time stressed the need to manage others' expectations. At times, managing expectations fueled decisions not to disclose having impairment. But for those whose work involved collaboration with others, all used a pragmatic approach to disclosure to communicate the ways a participant's impairment might impact their colleagues. For example, Betty decided to disclose that she had MS to project collaborators after an exacerbation put her in the hospital:

I needed to let these people who count on me at a distance to work my ass off know that maybe I'm not going to work my ass off. I mean, I had no idea that spring how things were going to be and it is still an issue for me – regulating fatigue and stress. These are ongoing issues. I know I get fatigued and stressed, and when I am fatigued my cognitive functioning isn't as, uh, up to my satisfaction, it seems different. So I have to, I needed to communicate in order to regulate the amount of demand that my fellow [colleagues] were making of me. (Betty)

Lionel has also learned over time that a pragmatic approach to disclosure helps avoid awkward situations when his impairment might interrupt the flow of his classroom:

The first time I did it, it was just that [a one liner] but the last time I did it, I told them, I was more specific about things like: I like the lighting to be less, that's why I have the blinds down. And eye contact is an issue, I mentioned that to them as well. And if we need – since there's computers in the classroom and they are all on their own computers, a lot of times they'll have issues trying to load a program and they're going to ask me about it and I won't be able to see the screen so I tell them that. I'm sort of trying to tell them how it will affect them. (Lionel)

Disclosure information about how one's impairment will potentially impact others is frequently used to set expectations for work colleagues. Importantly, this form of disclosure is also employed to manage expectations of intimates.

For people living with non-apparent or intermittent impairments, communicating ever-changing capabilities in order to manage the expectations of loved ones and social networks remains a challenge. Betty, diagnosed with MS during an exacerbation resulting in hospitalization, waited to tell her adult children until she was somewhat recovered. She still works hard to shield them from fears swirling around the uncertainty of her disease, but also wants them to understand why her energetic affection might wane at times. Betty explained:

I also sort of needed to tell them because again, sort of like talking to my [work] colleagues, I needed to have some context for them to understand if I can't, you know, give them energy and attention that they want at the time that they want it ... I needed to, I needed to kind of signal a tiny bit of vulnerability to them because my sense was they understood me to be invulnerable. They were ... The great thing is that I was able to convince them that everything is fine. I mean, they really believe my PR [public relations management] that I am fine. And they should, they should believe it. (Betty)

Indeed, managing one's "PR" can be a part-time job in itself for those living with non-apparent impairment. Nina uses social media to communicate changing impairment to her social circle. When Nina started using a wheelchair for traveling long distances, she decided to post pictures of her new assistive device on her Facebook account in order to forewarn folks about her changing condition. Nina reflected on that decision:

I don't go back to my hometown very often, but I do go every couple years, and wheeling down the main street, it's a small town. Um, and a lot of people either stayed there, or at least still have parents there and come to visit. And so I can pretty much guarantee that I will know somebody if I – if I do go downtown there. And, uh, rather than dealing with that, and answering all of the questions, or implied questions, um, I just put it out there. ... And I think part of it was – was that there are people who knew me as a physically healthy, athletic person, and so it would be, I think, a big surprise. Um, and so I was fielding that. (Nina)

Unlike Betty, Nina did not choose to disclose in order to reassure her social circle that “everything was fine” but to notify them that Nina would be functioning differently from the way she did when they last saw her. Notably, Nina used this strategy to reset her social circle's expectations of her in order to avoid having to explain her situation, not to invite one-on-one dialogue with her community.

Participants who disclosed experiencing impairment or a health condition that could lead to impairment frequently did so in order to communicate working conditions that could improve or remove barriers to productivity. Pragmatic disclosure is also used to set others' expectations, both in the workplace and with family and friends. Like Betty “signal[ing] a tiny bit of vulnerability” to her adult children or Lionel telling students how his low vision may impact them in the classroom, a pragmatic approach to disclosure means being selective in what and how to disclose in order to manage one's own image and to proactively facilitate conversations about changing capabilities.

Disclosure, and decisions to not disclose, weigh heavily on people's minds due to concerns about managing the ways others perceive disabled people. Disclosure decisions can also play an important role in asserting impairment as a different way of being, rather than a diminished state of being. When disclosure decisions serve to embrace disability, this approach is validating for people living with non-apparent impairment.

Validating disclosure

One-half of the participants¹ in this study described times when they intentionally decided to disclose in order to establish their differentness as authentic or legitimate, or in order to “weed out” people who did not hold their same values. I call this approach validating disclosure. Participants described incidents of validating disclosure as serving to invite dialogue, identify allies, or to signal one's identification with a disability community.

While several participants claimed to have “learned lessons” from engaging in confessional disclosure, many also reflected on the unexpected benefits of employing pragmatic approaches to disclosure. This process led Jake to experiment with validating disclosure. For example, he found that by

sharing information about the uncertainty of his degenerative disease and the possible side effects of the medications he takes to treat it, he began to benefit from an unusual openness in dialogue. Jake mused about one of the first times he employed this approach:

I think at the time I made it somewhat clear that I would, I would be the driver in being open if there were psychological or physical effects that I noticed, that I would talk to her about them and likewise if she noticed some pretty drastic changes in me, that I would like her to talk to me about it ... I think that by telling people to look out for those things I have given them more license than is typical in a social contract between two people, to comment on my emotional and professional outlook, which has largely been to the good. If I have been pissing someone off they are actually open to telling me that I've been pissing them off. [laughs] ... so we have had conversations about interpersonal interactions that may not have occurred otherwise ... I think there has been more open communication as a result of that. And that includes both professional colleagues as well as friends. (Jake)

Betty also used a validating approach to disclosing information about her impairment experiences with a few, select friends who shared her “analytical values.” These friends became important sounding boards for processing new information and deciding how to act on that information:

And so between the two of them we could talk about the human issues but also the scientific issues. You know, what is the evidence, what are the claims, what were the biases in these studies, what is the kind of bandwagon effect and all of that kind of stuff. ... So I was able to have that conversation with [Jeff] and [Sally] because we share a lot of the same analytical values and style of analyzing information but also share the same interests in terms of health and in terms of kind of being humane with oneself. (Betty)

Disclosing information solely for the purpose of sharing one's experiences opened channels of communication for participants with others in ways that helped them explore and normalize a new way of being.

Accepting a new way of being can be difficult for individuals who often look like nothing has changed for them, despite having been injured or diagnosed with chronic illness. Due to the invisibility of these impairments, participants discussed the challenges of identifying others with similar impairments or disability allies. Molly, who conducts research with children with traumatic brain injury, often uses her research topic to assess her “audience” or allies and insiders in the traumatic brain injury community:

There's [a reaction] to my research – that identifies for me who knows and who doesn't, who's in a community, who's not. And if they're in the community, then I further disclose, but if they're not ... And they might say, like, 'So how did you get involved in that?' and I say, 'Well, I was focused on policy, and then I had my own injury, and I moved to special ed,' and I leave it at that. But I've really created new ways to gauge who my audience is – and who's in the know and who isn't ... (Molly)

I responded by asking Molly what it meant for her when she discovered someone was “in the community.” She replied:

It means I’m not alone. It means I’m not alone. [Pause] It means I have one more comrade in this fi – in this fight. It means to – to –for understanding. So –[sigh] – [Pause] it also triggers the desire to help. It triggers my passion to – for service to others, and if I find out they’re in the community, then the next stage for me is to find out where they are in their recovery, what resources do they need, where can I help guide them. How they can guide me comes four steps later, but it immediately helps me identify someone that I can connect to and possibly lend my strength. (Molly)

In such instances, Molly’s decision to disclose has nothing to do with asking for favors, justifying her behavior, or acquiring practical accommodations; her decision to disclose serves only to confirm that she is “not alone” in her experience of disability and to “connect to” others.

Jake also discussed his decision-making process of how much information to disclose to people. Having held several jobs since diagnosis, and experiencing flare-ups of impairment in many of them, he has developed a brief set of rules he communicates to employers during pragmatic disclosure. How they respond to those rules determines what levels of information he later shares. In the end, he admits, he often uses disclosure as a way of evaluating the character of others:

There are people with whom I will have a conversation and there are people with whom I won’t. And were they to respond to ‘you have MS and you have requested that I play by your rules in that and I am going to say no’ – my immediate response is ‘Fuck you. You’re not worth talking to.’ And I will deal with unemployment, I will deal with looking for another job, I will deal with all of these things. There are character judgments that comes through in sequence and if someone is willing to go that route just based on divulging, disclosing the disease, what sort of integrity can you expect from that crowd going forward? Too many question marks. No thank you. (Jake)

For Jake, being part of a specific community is less important than sharing his values more broadly. Disclosing information about his chronic illness creates an opportunity for his audience to reveal something about themselves, and enables Jake to identify individuals he may want to further connect with, or not.

Validating approaches to disclosure serve not only to gauge reactions of others, but often to simply embrace a new way of being. Over the course of nearly 20 years living with chronic illness, Nina has used a variety of mobility assistive devices. Nina reflected on ways that the visibility of assistive devices shifted how and what she disclosed: in some circumstances giving her less control over information about her impairments, and in others making disclosure altogether unnecessary. In the first decade or so of living with the disease, Nina employed pragmatic disclosure approaches to communicating changing conditions regarding her mobility:

I think that disclosing was easier for me than coming to terms with my own feelings. Um, I think that disclosing to people, like I said, was more about disclosing that there were certain things that weren't working with me, rather than the fact that I was disabled. (Nina)

As Nina began using a wheelchair more consistently, she deliberated on how to handle disclosing to her wider community her new way of being. Ultimately, she decided to approach disclosure with a validating flare:

So I joined Facebook, and I created this photo album of different views of different wheelchairs in different positions. And, uh, only once I had that in place then I friended a bunch of people from my past who had no idea. And so I had all of these photos of a wheelchair. I had a link to an article I had written about MS and traveling. So sort of indirectly letting people know that I had: (1) a disease diagnosis; and, (2) was using a wheelchair. (Nina)

As previously discussed, Nina's use of social media to manage others' expectations about her is a pragmatic form of disclosure. However, disclosing in this way also served a non-pragmatic, validating purpose of embracing a new identity. I specifically asked Nina if she felt this disclosure decision played a role in her own identity development, and she responded by laughing and saying: "Yes, my album is called 'Rolling Out of the Closet'."

Nina was not alone in using the analogy of 'coming out' with regards to disability disclosure. Molly also used this phrase. When asked about decisions to disclose when disclosure might not serve any practical purpose, Molly replied:

Why do I need to tell the group? Because I want them to see me holistically. I want them to see my passion and hear a little bit of my story, and I don't ever wanna cut something out of my life in my identity. ... So, yes, I bring up parts of my past even if I'm in a room that couldn't care less. (Molly)

Disclosure intended to invite dialogue about, identify others with, or confirm one's own disability identity serves the primary purpose of validation. This form of disclosure does not hinge upon the reactions of others, but sits squarely in the intentional self-declaration of living with difference. In this way, these disclosure acts resist popular narratives of stigma or stereotypes by exposing friends, colleagues, and coworkers to peers who look 'normal' but actively disrupt that assumption. As Jake summarized his decisions to disclose even when technically unnecessary:

The pithy answer is: without, without balancing the equation, the other side can do whatever they want. They can make a number of assumptions for good or ill. But by grounding everyone's reality in what I understand in the present, odds are the moment and moving forward will be more productive and emotionally healthy. And that results from open communication and dialogue. (Jake)

Of all the forms of disclosure, validating disclosure practices seemed to have the greatest impact on robust disability identity formation.

Discussion

This study's examination of disclosure decision-making by individuals with non-apparent impairments provides direct insight into the lived realities of the social model of disability. When we take seriously the idea that the socially constructed status of disability emerges in the interactions between an individual's way of functioning and the social or built environment (Linton 1998; Longmore and Umansky 2001; Switzer 2003; Barnes and Mercer 2003; Shakespeare 2013), we acknowledge both the importance and messiness of disclosure decision-making among this population. As a mechanism of identity management, different forms of disclosure were employed by participants in different circumstances. As moments of identity revelation, there was no evidence that one disclosure form inevitably leads to another or that these forms of disclosure neatly mapped onto time since diagnosis or injury. Rather, participants related employing different forms of disclosure during different circumstances; and no participant reporting using any one form of disclosure exclusively.

These findings have three important implications when put into the context of other research on disability disclosure. First, this study empirically demonstrates the limitations of analogizing the experience of 'coming out' between people with non-apparent impairments and members of the LGBTQ community. Unlike models developed through studying queer disclosure experiences that have shaped our understandings of disclosing 'invisible identities' more broadly (Corrigan and Matthews 2003), those with acquired, non-apparent impairments do not indicate any systematically evolving 'steps' to disclosure decision-making; this process remains highly contingent upon the immediate social circumstance. Furthermore, by tracing disclosure moments as 'autobiographical occasions' (Zussman 2000), these findings reveal that disclosure decision-making does not linearly map onto any one identity, highlighted, for example, by Molly and Jake's 'testing' of their audience to determine not whether, but how much, to disclose.

As the narratives presented here demonstrate, these analytical categories of disclosure – confessional, pragmatic, and validating – are not mutually exclusive. Indeed, one act of disclosure may serve several purposes. When Dahlia described being 'caught' crying by her supervisor and disclosed to him, she subsequently discovered that he too was living with impairment. In this sense, her disclosure may have been confessional but the response she received served to validate her own experience. The distinction I draw in this analysis is that while disclosure may serve many purposes, the intention behind disclosure is what determines its form. In some cases, the intention may also be two-fold. Nina's pragmatic approach to letting her social network know that she was using a wheelchair was for practical purposes.

However, naming her album “Rolling Out of the Closet” is telling in terms of her burgeoning sense of disability identity.

Impairment disclosure is an important mechanism for managing one’s identity in relation to disability. Deciding whether or in what fashion to disclose impairment is a decision to make oneself vulnerable to the judgments and preconceived ideas of others about disability. As such, disclosure can be used to further distance oneself from a disability identity, such as Dahlia’s reluctance “to ask people for something,” a practice that did not align with her self-image. Disclosure can also enable people to frame their experiences in ways that are empowering and validating, such as Molly’s reluctance to “cut something out of my life in my identity.”

Decisions to disclose are in and of themselves constitutive moments of identity formation. Siebers (2008, 8) defines identity as “narrative responses to and creations of social reality” that serve as vehicles for “inserting persons into the social world.” Experimenting with different forms of disclosure involves presenting slightly different narratives of how one fits into their social world. The way Betty framed her situation – her PR – to her adult children reified her self-image as a resourceful, self-directed person. Jane’s decision to disclose to an employer, for the first time, created a locus for her to stitch her daily experiences with Lyme symptoms together with her self-image as an employee with a strong work ethic. In one of the opening quotations to this piece, Molly describes disclosure as “trial by fire,” reflecting the impact that disclosure has not only on participants’ relationships with others, but on their own self-narratives. This insight has led Molly to regard opportunities for disclosure as moments when she can help others see her “holistically.”

Disclosure serves the purpose of informing another party of impairment, but also signifies other identity characteristics. Disclosure signals to audiences a status that may be shared or empathized with, potentially encouraging others to express their own experiences with impairment or at least let them know they “are not alone.” Different forms of disclosure impact individuals’ self-perceptions and signal to others political alliances, rights awareness, or even an apolitical view of disability. Confessional disclosure is used to explain a perceived deficiency in one’s performance or to justify asking for something out of the ordinary. Pragmatic disclosure conveys impairment information in very practical terms, using disclosure to enlist others in reducing barriers to productivity in built and social environments. Validating disclosure legitimizes disability identity, signaling a political identity that resists or calls out systems of oppression against a shared, minority status. For individuals living with acquired, non-apparent impairment whose experiences are frequently characterized by pain, uncertainty, and invisibility, disclosure decision-making plays an important role in developing a disability identity.

Funding

This work was supported by Law and Social Sciences Division National Science Foundation [Dissertation Improvement Grant No. SES-1251433].

Disclosure statement

The author has no conflict of interest.

Note

1. Dahlia, Nina, Betty, Jake, Sally, and Molly.

ORCID

Heather D. Evans  <http://orcid.org/0000-0002-7741-0054>

References

- Barnes, C., and G. Mercer. 2003. *Disability*. Cambridge, U.K.: Polity Press.
- Bathmaker, A. & Harnett, P., Eds. 2010. *Exploring Learning, Identity & Power through Life History & Narrative Research*. New York: Routledge.
- Bowen, G. 2006. "Grounded Theory and Sensitizing Concepts." *International Journal of Qualitative Methods* 53:1–9. <http://www.ualberta.ca/~ijqm/>
- Bowker, N., and K. Tuffin. 2010. "Disability Discourses for Online Identities." *Disability & Society* 17 (3):327–44. doi:[10.1080/09687590220139883](https://doi.org/10.1080/09687590220139883)
- Brune, J. & Wilson, D., Eds. 2013. *Disability and Passing: Blurring the Lines of Identity*. Philadelphia, PA: Temple University Press.
- Cameron, C., and J. Swain. 1999. "Unless Otherwise Stated: discourses of Labelling and Identity."
- Charmaz, K. 1995. "The Body, Identity, and Self: Adapting to Impairment." *The Sociological Quarterly* 364:657–80. doi:[10.1111/j.1533-8525.1995.tb00459.x](https://doi.org/10.1111/j.1533-8525.1995.tb00459.x)
- Chase, S. 2005. Narrative Inquiry. In N. Denzin & Y. Lincoln, Eds., *The SAGE Handbook of Qualitative Research*, 3rd Ed. pp. 651–79. Thousand Oaks: Sage Publications.
- Chatterjee, R. 2010. "Information and Communication for Persons with Disability." *Global Media Journal: Indian Edition*, Dec 2010: 1–10.
- Chaudoir, S., and D. Quinn. 2010. "Revealing Concealable Stigmatized Identities: The Impact of Disclosure Motivations and Positive First-Disclosure Experiences on Fear of Disclosure and Well-Being." *Journal of Social Issues* 663:570–84. doi:[10.1111/j.1540-4560.2010.01663.x](https://doi.org/10.1111/j.1540-4560.2010.01663.x)
- Coopman, S. J. 2000. "Disability on the Net." *American Communication Journal* 33:1.
- Corrigan, P. W., and A. K. Matthews. 2003. "Stigma and Disclosure: Implications for Coming out of the Closet." *Journal of Mental Health* 12 (3):235–48.
- Cortazzi, M, et al. 2001. Narrative Analysis in Ethnography. In P. Atkinson. Eds. *Handbook of Ethnography*. pp. 384–94. London: Sage Publications Ltd.

- Evans, H. D. 2017. "Un/covering: Making Disability Identity Legible." *Disability Studies Quarterly* 371. doi:[10.18061/dsq.v37i1.5556](https://doi.org/10.18061/dsq.v37i1.5556)
- Frank, A. 1991. *At the Will of the Body: Reflections on Illness*. Boston, MA: Houghton-Mifflin.
- Frank, A. 1995. *The Wounded Storyteller: Body, Illness and Ethics*. Chicago, IL: Chicago University Press.
- Furr, J., A. Carreiro, and J. A. McArthur. 2016. "Strategic Approaches to Disability Disclosure on Social Media." *Disability & Society* 31 (10):1353–68. doi:[10.1080/09687599.2016.1256272](https://doi.org/10.1080/09687599.2016.1256272)
- Goffman, E. 1963. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster, Inc.
- Heyer, K. 2002. "The ADA on the Road: Disability Rights in Germany." *Law Social Inquiry* 274:723–62. doi:[10.1111/j.1747-4469.2002.tb00980.x](https://doi.org/10.1111/j.1747-4469.2002.tb00980.x)
- Heyer, K. 2007. "A Disability Lens on Sociolegal Research: Reading *Rights of Inclusion* from a Disability Studies Perspective." *Law & Social Inquiry* 321:261–93. doi:[10.1111/j.1747-4469.2007.00058.x](https://doi.org/10.1111/j.1747-4469.2007.00058.x)
- Irvine, A. 2011. "Something to Declare? The Disclosure of Common Mental Health Problems at Work." *Disability & Society* 26 (2):179–92. doi:[10.1080/09687599.2011.544058](https://doi.org/10.1080/09687599.2011.544058)
- Kaye, S. H. 2000. *Computer and Internet Use among People with Disabilities*. Washington, DC: National Institute on Disability and Rehabilitation Research, U.S. Department of Education.
- Laslett, B. 1999. "Review: Personal Narratives as Sociology." *Contemporary Sociology* 284: 391–401. doi:[10.2307/2655287](https://doi.org/10.2307/2655287).
- Leonard, L., and J. Ellen. 2007. "The Story of My Life': AIDS and 'Autobiographical Occasions.'" *Qualitative Sociology* 31 (1):37–56. doi:[10.1007/s11133-007-9086-5](https://doi.org/10.1007/s11133-007-9086-5)
- Linton, S. 1998. *Claiming Disability: Knowledge and Identity*. New York: New York University Press.
- Longmore, P., and L. Umansky. 2001. *The New Disability History: American Perspectives*. New York: New York University Press. doi:[10.1086/ahr/107.5.1523](https://doi.org/10.1086/ahr/107.5.1523).
- Medjesky, C. 2008. "Disabusing Disability: Negotiating Disability Identity through Anecdote." In *Presentation to the 2008 National Communication Association Conference*, San Diego, CA, USA.
- Oliver, M. 1992. "Changing the Social Relations of Research Production?." *Disability, Handicap & Society* 7 (2):101–14. doi:[10.1080/02674649266780141](https://doi.org/10.1080/02674649266780141)
- Petersen, A. J. 2011. "Research with Individuals Labeled 'Other': Reflections on the Research Process." *Disability & Society* 26 (3):293–305. doi:[10.1080/09687599.2011.560413](https://doi.org/10.1080/09687599.2011.560413)
- Pilling, M. D. 2012. "Invisible Identity in the Workplace: Intersectional Madness and Processes of Disclosure at Work." *Disability Studies Quarterly* 331. doi:[10.18061/dsq.v33i1.3424](https://doi.org/10.18061/dsq.v33i1.3424)
- Plummer, K, et al. 2001. The Call of Life Stories in Ethnographic Research. In P. Atkinson., Eds. pp. 395–406 *Handbook of Ethnography*. London: Sage Publications Ltd.
- Price, M., M. Salzer, A. O'Shea, and S. L. Kerschbaum. 2017. "Disclosure of Mental Disability by College and University Faculty: The Negotiation of Accommodations, Supports, and Barriers." *Disability Studies Quarterly* 372. doi:[10.18061/dsq.v37i2.5487](https://doi.org/10.18061/dsq.v37i2.5487)
- Renfrow, D. 2004. "A Cartography of Passing in Everyday Life." *Symbolic Interaction* 274: 485–506. doi:[10.1525/si.2004.27.4.485](https://doi.org/10.1525/si.2004.27.4.485)
- Riessman, C. 1993. *Narrative Analysis*. Newbury Park, CA: Sage Publications.
- Saltes, N. 2012. "Disability, identity and Disclosure in the Online Dating Environment." *Disability & Society* 28 (1):96–109. doi:[10.1080/09687599.2012.695577](https://doi.org/10.1080/09687599.2012.695577)
- Samuels, E. 2003. "My Body, my Closet: invisible Disability and the Limits of Coming-out Discourse." *GLQ* 91-2:233–55. doi:[10.1215/10642684-9-1-2-233](https://doi.org/10.1215/10642684-9-1-2-233)

- Sarrett, J. 2017. "Interviews, Disclosures, and Misperceptions: Autistic Adults' Perspectives on Employment Related Challenges." *Disability Studies Quarterly* 372. doi:[10.18061/dsq.v37i2.5524](https://doi.org/10.18061/dsq.v37i2.5524)
- Schweik, S. 2009. *The Ugly Laws: Disability in Public*. New York: New York University Press.
- Shakespeare, T. 1996. Disability, identity and difference. In C. Barnes and G. Mercer, Eds. *Exploring the Divide.*, pp.94–113. Leeds: Disability Press.
- Shakespeare, T. 2013. The Social Model of Disability. In L. Davis Ed. *The Disability Studies Reader*. 4th Ed. pp. 218–25. New York: Routledge.
- Shapiro, J. P. 1994. *No Pity: People with Disabilities Forging a New Civil Rights Movement*. New York: Random House LLC.
- Siebers, Tobin. 2008. *Disability Theory*. Ann Arbor, MI: The University of Michigan Press.
- Switzer, J. V. 2003. *Disabled Rights: American Disability Policy and the Fight for Equality*. Washington D.C.: Georgetown University Press.
- Tierney, W. 2000. Undaunted Courage: Life History and the Post Modern Challenge. In N. Denszin and Y. Lincoln Eds. *Handbook of Qualitative Research*. pp. 537–53. Thousand Oaks, CA: Sage Publications.
- Yoshino, K. 2006. *Covering: The Hidden Assault on Our Civil Rights*. New York: Random House Publishing.
- Zola, I. 1982. *Missing Pieces: A Chronicle of Living with a Disability*. Philadelphia, PA: Temple University Press.
- Zussman, R. 1996. "Autobiographical Occasions." *Contemporary Sociology* 252:143–8. doi: [10.2307/2077159](https://doi.org/10.2307/2077159)
- Zussman, R. 2000. "Autobiographical Occasions." *Qualitative Sociology* 231:5–8. doi: [10.1023/A:1005447331522](https://doi.org/10.1023/A:1005447331522)