Excerpt from *You Get Proud By Practicing*, Laura Hershey:

“These are all ways

Of getting proud.

None of them

Are easy, but all of them

Are possible. You can do all of these things,

Or just one of them again and again.

You get proud

By practicing.”

Laura Hershey’s *You Get Proud By Practicing* clearly articulates the importance of individual experience within the disability pride movement. As the disability pride movement grows more robust and mainstream, it becomes increasingly critical to emphasize the individual experiences that people have with disability. And as it becomes more common to openly claim a disability identity and embrace the pride of having a disability, it also becomes easier to ignore that the intersection between disability and pride is incredibly nuanced. Pride ebbs and flows just like all other feelings, and feeling proud for some can be a constant battle with various successes and shortcomings. As Hershey says in her poem, pride is not easy, and just like all other skills, pride takes practice.

In this paper, I’d like to focus on how pride takes form for individuals with invisible disabilities. My central question is, what does it look like to make “invisible” disability, “visible”? There is so much variance within the disability community with regards to agency in being labelled disabled. People with obvious physical disabilities have little to no agency in being labelled disabled by society because people are quick to notice physical disabilities and label these individuals as disabled. On the other hand, people with invisible disabilities, such as mental illness or other less obvious physical/ cognitive disabilities, have more agency with whether or not they are labelled as disabled by society. This agency has both positives and negatives. There is clear privilege that comes with agency, as there are benefits to not having society automatically label a person as disabled (i.e. less upfront discrimination and stigma). However, one drawback is that if individuals with invisible disabilities want to claim this disability identity, then they must continuously do so through explicit explanations or expressions. Additionally, invisible disabilities tend to be more heavily stigmatized, both within the disability community and within society as a whole. In claiming a disability identity, individual disability narratives become an important and accessible avenue to make an invisible disability, visible. These individual disability narratives can take form as concrete “coming out” stories shared on various platforms (often on the internet), or they can take place in less explicit ways throughout the course of one’s own life experiences -- creating a narrative way of expression in one’s own physical life that works to make invisible identity more visible. I’m going to explore both concrete “coming out” stories and individual narrative stories from my own personal family experience with disability that demonstrate what it can look like to take an invisible disability and make it more visible.

Here are ways that pride can look for individuals with invisible disability who are working towards making their disabilities more visible. Claiming any identity, including a disability identity, is never a linear process. The following includes disability narratives that highlight just how nuanced this process of “coming out” as disabled or simply not intentionally hiding a disability can be for individuals with invisible disabilities.

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It’s 105 degrees on a sunny Tuesday in Frisco, Texas. I walk the aisles of Target with my mom, my soccer teammate, and her father. We pass the aisle that houses nutrient and protein drinks typically meant for young kids or old adults. My mom looks me in the eyes and I nod at her. She picks up a six-pack of Boost Plus Chocolate Sensation -- the least nauseating of the flavors -- and throws it into the cart. The moment passes, and the four of us continue to shop. I think we go to the granola bar aisle next.

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Excerpts from “Everyone is Going Through Something” -- an article by Kevin Love in *The Players Tribune*:

“On November 5th, right after halftime against the Hawks, **I had a panic attack. It came out of nowhere**. I’d never had one before. **I didn’t even know if they were real. But it was real** — as real as a broken hand or a sprained ankle. Since that day, almost everything about the way I think about my mental health has changed.”

“It was **like my body was trying to say to me, You’re about to die**. I ended up on the floor in the training room, lying on my back, **trying to get enough air to breathe**.”

“Call it a **stigma** or call it **fear or insecurity** — you can call it a number of things — but what I was worried about wasn’t just my own inner struggles but **how difficult it was to talk about them**. I **didn’t want people to perceive me as somehow less reliable as a teammate**, and it all went back to the playbook I’d learned growing up.”

“In the short time I’ve been meeting with the therapist, I’ve **seen the power of saying things out loud** in a setting like that. And it’s **not some magical process**. It’s **terrifying** and **awkward** and **hard**, at least in **my experience** so far.”

All of these quotes are excerpts from an article that Kevin Love published in *The Players Tribune* just a few days ago on March 6, 2018. Love is a famous professional basketball player on the Cleveland Cavaliers NBA team, and he publically shared his recent experiences with anxiety -- with regards to how it affects him on the basketball court and in his personal life. This article serves as Love’s “coming out” story with a mental illness that he is learning to deal with. His narrative demonstrates how this process of claiming a disability identity is messy. Even as a respected and widely-renowned athlete, Love expresses his self-doubt about making his invisible disability, visible because he didn’t want to face the stigma or seem weak to his teammates.

Love also touches on how dealing with disability is a nonlinear process. He describes the therapy process as “terrifying and awkward and hard” in his personal experience. However, he also recognizes “the power of saying things out loud” in his treatment process. In a way, this narrative that he posted in *The Players Tribune* seems to mirror his therapy process as he explained it so far. He posted personal information in a very public setting that makes him more vulnerable, yet with this vulnerability, comes the power of being able to be open and free to claim his own true identity.

Love’s “coming out” narrative with his anxiety has even more power behind it than most other disability narratives, as Love’s public platform is on a much larger scale. Famous people sharing their individual disability narratives not only serves the function of helping the individual with the disability claim their own identity, but it can be important as a way to help others without that platform feel comfortable sharing their own experiences. Whether or not the people who read the narratives of famous people actually come forward and publically claim a disability identity, narratives like Love’s can help people deal with their own struggles. Love’s narrative about having a panic attack on the court has the potential to reach a lot of people and feel incredibly validating -- as he has the ability to share his story on such a large platform. Many news sources, such as ESPN, within even the first few hours after Love published his narrative, wrote about Love’s story and shared it on their own large social media platforms. Just within the first 24 hours, Love’s story has been shared widely in sports news-media and social-media platforms -- reaching many around the country and the world.

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It’s 7:30 PM on a beautiful August day in Bethany Beach, Delaware. The sun is just beginning to set, and streaks of pink start to vaguely appear in the sky. I sit next to my mom at a long wooden table filled with 15 or more members of our extended family -- aunts, uncles, cousins, grandparents. She picks up her glass of wine with her right hand and raises it to her lips for a sip. Her hand begins to tremor and she can’t steadily bring the glass to her mouth without spilling. She closes her eyes and take a deep breath. Instead of one hand, my mom places both hands around her wine glass and slowly brings it to her lips. She takes a sip.

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Excerpts from “I am Springsteen” -- an article by Lorrie Mchugh-Wytkind in the *Huffington Post*

“I am Springsteen. And so are countless others. We are the **survivors of clinical depression, bipolar disorder and other mental health conditions that do not get much attention in our country unless something goes terribly wrong**. We are the people who **keep our heads down, don’t talk about our suffering, even hide due to the stigma** that goes hand-in-hand with mental health disorders. We are the people who **don’t have the platform to raise awareness about our struggles.** We are Springsteen without a microphone.”

“Bruce Springsteen’s recent opening up about his bouts of clinical depression made me and I dare say many others **feel normal**. It **validated** my visceral reaction to statements like, “what do you have to be depressed about, you have a good life.” **If Springsteen could be arguably the biggest rock star in the world and, yet, also be depressed, perhaps I wasn’t so ‘odd’.**”

“Perhaps I **shouldn’t be ashamed** that it wasn’t just a matter of having a bad day; **it was a matter of having an illness that requires twice daily doses of medicines, therapy and even watching what I eat.”**

**“There is no magic wand for mental illness.”**

These quotes are all excerpts from a *Huffington Post* article “I am Springsteen” by Lorrie Mchugh-Wytkind. Just as Love’s narrative has been shared all over social media and news outlets, Springsteen’s memoir, which Mchugh-Wytkind draws heavily on in this piece, was widely read and shared in the news. Mchugh-Wytkind’s narrative is inspired by Bruce Springsteen’s memoir where he shared his struggles with clinical depression -- his own coming out narrative. Springsteen’s influence as a famous rockstar with a large public platform in turn encouraged Mchugh-Wytkind to claim a disability identity and feel empowered by her experience. Again, the weight behind famous narratives can be seen as Mchugh-Wytkind says she felt “validated” and “normal” when reading about Springsteen’s experiences.

In her disability narrative, Mchugh-Wytkind brings up an important point about the public rhetoric surrounding disability, and especially mental health. She asserts that mental health does not get much attention unless “something goes terribly wrong.” Shedding light on institutional problems -- such as the hegemonic association of mental health disorders with violence, deviance, fear -- is one way that people can make invisible disability visible. Mchugh-Wytkind raises an important point that mental health disorders are constantly present, but only become visible when associated with a tangible catastrophe. Making the everyday mental health disorders, that most people feel the need to hide, more a part of the mainstream rhetoric will help to change the discourse around mental health disorders. “Coming-out” narratives like Mchugh-Wytkind’s not only serve as a space for individuals to claim their own disability identities, but it serves the crucial role of making conversation about mental health and other invisible disabilities seem less taboo. This is what it looks like to make the invisible, visible -- and it’s incredibly important.

Within her piece, Mchugh-Wytkind also highlights the nuances of claiming disability as an identity and feeling the associated pride. She admits that while she is now realizing that she “shouldn’t be ashamed,” her disability requires constant work and a lot of patience. She shares her experiences with intense therapy, medicine, and other treatments that have required patience and persistence over a lifetime. She talks about keeping her head down and “hiding” due to stigma. While she is claiming her identity loud and proud in this piece as an individual with an invisible disability, she also explains how she is influenced to sometimes hide this very disability. She simultaneously holds pride and shame within her own identity surrounding disability -- a fact that clearly illustrates the nuances within disability pride.

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It’s 6:28 PM on a Monday night, and she walks into a room where everyone sits around a table with their mostly empty dinner plates, eating their last few bites before the Whitman-Walker Health board meeting begins at 6:30 PM. She always shows up at 6:28 PM, not at 6:00 PM when all of the other board members eat dinner together. She quietly takes her seat and waits the final two minutes for the meeting to start.

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It’s 7:30 PM on this same Monday night. She continues to sit in her place around the table, participating in the lengthy board meeting. She reaches into her purse and pulls out a pill-box. She pours all of her evening pills into her hand, and with one swift motion, she swallows the many pills with a single sip of diet coke. With a snap shut of the pill box, she puts it back into her purse and continues participating in the board meeting.

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Excerpts from Ona Gritz’s testimony in her introduction to her poetry section in *Beauty is a Verb: The New Poetry of Disability*:

“I walk as though favoring a sore foot. ***Barely noticeable*, people said.** These comments were meant to be compliments. **I was lucky, it seemed, because I wasn’t *too* different. Because I could more or less pass**” (191).

“But mostly when I thought about having cerebral palsy, what I focused on was how people saw me. It pained me to think that someone might not find me pretty because of my uneven legs and awkward gait. **I didn’t know that worrying over such things is a kind of luxury**” (192).

“**I’ve had cerebral palsy since the day I was born, but it wasn’t until my son was born that I truly experienced disability** [...] What she didn’t understand was that the one hand I had that was capable of pouring cereal and milk, of using a spoon, was the same one hand that could safely prop an infant’s head. **Hardly anyone knew this about me, and I found that fact frightening**. Faced with caring for my baby and myself, **I no longer wanted to pass as able-bodied**. **I wanted to be looked at squarely, limitations and all, so I could get the practical advice and physical help I needed. For that to happen, I had to take my disability out from the bottom of the closet and claim it”** (192).

These excerpts from Ona Gritz’s introduction to her poetry hit on the complexities involved with having an invisible disability. The privilege. The fear. The stigma. The shame. The relative ease. The relative difficulties. The contexts.

Gritz has mild cerebral palsy, which is not typically thought of as an invisible disability, but rather is usually thought of as visible. However, in the context of Gritz’s experience, her cerebral palsy is more-or-less invisible as she has only a minor visible limp, and in her past, tried to hide her disability. She says that “hardly anyone knew this about me” -- meaning that her disability was invisible to most of the people in her life, even though it is physical.

One salient theme in Gritz’s narrative is about the concept of “passing” as non-disabled. Gritz shares that she spent most of her life passing as able-bodied, and was often told by the people close to her that she easily passed, as if this was something positive, lucky, vital to her success. However, Gritz’s perspective completely changed once her son was born. Her cerebral palsy made caring for her son safely almost impossible, as one of her hands does not have the strength or coordination to hold a child and do most other manual tasks. She was then in a position where most people did not know about her disability, yet she needed physical help and support. Gritz says that she “no longer wanted to pass as able-bodied.” She wanted “to be looked at squarely, limitations and all” so should could get advice and help. To do so, Gritz took her “disability from the bottom of the closet and [claimed] it.” Gritz’s narrative not only serves the purpose of helping her join the disability community by sharing her experiences in this anthology of disability poetry, but it also illustrates a concrete example of someone explicitly making her invisible disability, visible.

For Gritz, the decision to engage with disability pride stemmed from her child. Gritz’s child suddenly presented as this need that she could not care for without resources, and claiming her disability identity allowed her get the help to care safely for her child. Again, individuality within disability narratives is so clear. Gritz never really had this burning need to claim her disability identity for herself until it became a problem for her child. People share their disability narratives for a variety of reasons -- some from internal need/ passion, some from outside inspiration, some from external motivators. The reasons are endless.

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Excerpts from testimonials of youth about disability pride from the National Council on Independent Living:

Responses to question **“Do you feel a sense of disability pride?”**

“The **short, easy answer is yes**. However, it’s **not a cut and dry, yes** I am proud and that’s it. It’s a **continual fight to be even more proud than the day before** [...] It’s ok to not feel proud, there are **days that I definitely don’t**, and there are days where I am **constantly apologizing** [...]. But the next day I have to start over, and you really don’t get to stop. **It’s an awareness of outside ableism, which contributes to internalized ableism, and unfortunately ableism, like any other form of oppression, is not suddenly going to disappear, we have to be constantly fighting back against these forces**.” –Priya Penner, 19

“So, I feel like the way that I think about pride… **I would probably say no on instinct**, because I **don’t see the aspect of having an identity as something to be proud of.** But **for me pride is fighting against shame**, and that is something that myself and other autistic people have to do a lot of, because there are **so many messages out there about how there is an inherent lack of value in being autistic** and we have to **fight against those stereotypes** every day … but I’m **proud we try to do that**, I’m proud that even in these circumstances we’ve made a community and **I’m proud that I’m a part of that community**.” –Reid Caplan, 25

These two excerpts of testimonies from youth answering the question “do you feel a sense of disability pride?” highlight how people can view disability pride/ identity in different ways. Penner instinctually responds “yes,” while Caplan instinctually responds “no.” However, in explanation, both go on to complicate their responses -- once again illustrating the nuances within disability pride.

Penner clearly expresses that while she has pride, it is nonlinear and ebbs and flows depending on the day and context. Penner describes her relationship with disability pride as a “continual fight” in which “you don’t really get to stop.” So while she sees her pride as something she is in contention with, she also sees the fight as necessary and productive. Penner extends her relationship with disability pride as a form of resisting ableist oppression. Even though she has a messy struggle with feeling proud of her disability, she asserts that this battle to be proud is exactly what will combat systematic oppression of disabled people. For Penner, part of making her disability visible and public is fighting against the systems of oppression that work to disable her.

On the other hand, Caplan does not proudly identify with a disability identity. Rather, he feels that having disability pride has more to do with “fighting against shame” and finding a place within the disability community (specifically the autism community in Caplan’s case). Caplan’s experience with his disability has been that society attaches a lack of value to his life as an autistic man. By sharing his testimony, Caplan is making autism more visible -- and therefore fighting against the common rhetoric that devalues the autistic life. Even though he does not personally identify with individual disability pride within his own identity, he is still making his disability more visible by fighting against stereotypes and finding a place in the autism advocacy community. Here, through his narrative, it is clear that even though pride is not explicitly part of his self-identity, he is proud to be part of a community that partakes in disability pride. Caplan can be involved in the pride community, without claiming disability pride as part of his own identity -- another way in which disability pride and identity is an individual experience for all.

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It’s hour two of a seven hour flight from Washington, D.C. to Sacramento, California. She’s sitting in the window seat of a three-person row and looks out the window to see that the plane is in the middle of a cloud. All of the people around her are either engrossed in their screens or sleeping. She pulls out her RO DBT (Radically Open Dialectical Behavioral Therapy) workbook -- another type of therapy that her treatment team recommended. She reads the cover, turns to page one, and dives in.

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