

The 'Othered' Sister: Family Secrets, Relationships, and Society  
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**Abstract:** Through auto-ethnography, the intersection between family culture and a hegemonic culture of normalcy is explored. One sister's investigation of disability, as manifested through shared family secrets, acts of resistance against the public stare, segregation and isolation, and notions of incompetence, unveil evidence of historical oppressive practices.

**Keywords:** auto-ethnography, disability, normalcy

I will never forget the phone call that came in the middle of a cold night back in February of 1984. On the other end of the line I could hear my mother's hollow words, "Tom's gone." Seared in my brain is the memory of confusion, wondering where my brother could have disappeared to. He did not drive, he had never gone off on his own before, and it was three o'clock in the morning. Where would he be? Patiently, my mother repeated, "He's gone, Missy. Tom died."

At that moment, the world slipped away from me. A chasm had been opened and I was being swallowed inside it. Up until that point, life had seemed so certain, but suddenly nothing made sense. I thought if I could only understand what had happened, then perhaps the pieces would fit together again. The scene that played out repeatedly in my head, as clear as if I had been there, provided no comfort to me. My mother on the phone with the life squad, my father sitting on the edge of the bed holding my brother's hand, his last look, his last breath. How the medical staff worked diligently to resuscitate him. In the end, Tom was still gone.

I have told this story, and written it, and rewritten it, countless times over the years, along with others that mark my life. Our stories of lived experiences signify our uniqueness and individuality, and the telling of these stories says something about our sense of self and how and where we fit in the world. Hidden in these stories, however, are also our connections with others. Sometimes they are only fragile filaments connecting us, but some connections act like heavy braided ropes. Regardless of the strength, these connections bind us with others. The ties developed through my stories are with other families who experience disability in a very intimate way because my brother - my big brother - was born with a disability.

Families that include someone with a disability are often resituated in the margins of society, set slightly askew from other families due to the unfamiliar and unknown. Wanting to avoid the voyeuristic nature of the abled, truths of family life are secreted away, like the practices of an underground society. One may know of them, or hear rumors and myths about them, but never truly understand what goes on in these families. Relatives who are compelled to hide the realities of family life may do so in response to the disabling social processes which contribute to misunderstandings of diversity in perceived ability.

Having a brother with an obvious ability difference, I know that bias toward individuals with disabilities does not occur in a vacuum affecting only those with a disability. The impact felt by family members is also very real. As private experiences can provide insight in to public

issues (Bullough & Pinegar, 2001), investigating my history as a sister of someone with a disability through a Disability Studies lens may offer hints into the historic, systemic exclusion (both social and physical) of individuals with disabilities that continues today. In reality, my history, just as the history of others, is a legitimate representation of a socio-historical moment in time (Bullough & Gitlin, 1995), and is investigated with this focus.

### Weaving Connections Between Self and History: Finding Threads Through Auto-Ethnography

Over the years, I have intermittently engaged in journaling about my life growing up in a family where disability was part of our everyday reality. In reflection, I noticed during each opportunity I had to either write or provide an oral history about my life, I consistently told the same stories, over and over again. What was the significance of these stories? Why did they touch me so deeply, and what impact did each have on my current beliefs and value system? An even greater question was what these stories might reveal about the social and political realities families confront everyday. Studying the spaces between the self and history, or what Bullough and Pinegar refer to as the “arena of practice” (2001, p. 15), became an integral aspect of this reflective process, as I sought connections between our family’s history and the public sphere. Like Wendell (2006), I was not satisfied with simply describing my family experiences, but strove to better understand them, dissecting and viewing them through a wide angle lens, investigating the intersection between society, identity, and representation, ultimately learning from these experiences.

As I began my quest, the old journals I had written were gathered, reflected upon, and analyzed. As I re-read the stories, I not only noted the repetition of stories, but also common phrasing and word choices. I tried to find what was lying beneath the stories by sifting through them, breaking each apart and looking for similarities across them including tone and emotion, as well as identifying what Mezirow (1997) referred to as any “transformative learning” (p. 5) incidents among them. The common elements were grouped into themes, and then investigated through a Disability Studies lens, looking for connections to the social and political ideologies that permeated my family’s life.

### A Tapestry Undone

The process of auto-ethnography was an unraveling of sorts, as I slowly, and sometimes painfully took apart, stitch by stitch, the fabric that had enveloped our lives, investigating the strength, texture, color, and even worn-out nature of each thread. There were times when I contested and even resisted what was materializing before me, a necessary phase of the auto-ethnographic process (Hamilton, Smith & Worthington, 2008). Understanding I hold legitimate knowledge as a sibling of someone with a disability, I juxtaposed the personal against the social and political representations of my experiences, recognizing the precarious balance that sometimes exists between biography and history (Bullough & Pinegar, 2001). Duarte (2007) suggested that auto-ethnographers situate themselves within context of a culture, group, or subgroup in order to compare experiences. For my purposes, I situated my stories alongside those of scholars in Disability Studies as a means for analysis, searching for shared epiphanies among us.

My story is a single thread in the tapestry that makes up the experience of disability across multiple people, recognizing that each of us “is a victim, vehicle, and ultimately a resolution of a culture’s dilemmas” (Bullough & Gitlin, 1995, p. 25). Through intense reflection, my hope was to analyze my responses to life events as a sibling of someone who was perceived as having a moderate to severe intellectual difference, to better understand the struggles families encounter in schools and society today related to inclusive practices, perhaps offering a fresh perspective on some established “truths”. The result was an unveiling of the connection between family secrets and peer responses to disability and difference, the public stare, segregation and isolation, and the negative connotations of mental retardation juxtaposed to a brother with competence and value.

## The Meaning Behind the Stories Family Secrets at the Heart of Family Culture

### Using Societal Thermometers

I learned the value of secrecy in my elementary years when a close friend stopped coming over to play. I had mistakenly confided in her about my brother hitting me during a moment of frustration. After that conversation, her parents would not allow her to return to my house, requiring us to play at her house alone. This one experience set the course of secrecy for me, not that I had anything to hide, but I learned early on that others may make judgments about my family or me due to inaccurate perceptions and accepted societal notions about disability. LeCompte (1993) talked about silencing as an act imposed on one by another, when people are “deprived of voice without their consent” (p. 10). For siblings, it is not that we lack the ability to speak for ourselves or share our stories, but when we do share our stories, we are often ostracized. This results in a deprivation of voice.

As a consequence, I did not announce to my friends that I had a brother with a disability, just as I never announced anything about my sisters, and I invited only a select few to my home. If friends visited, I watched with curiosity to see how each would react to our family makeup. My friends were my societal thermometers, testing the temperature of our cultural climate. How they responded to my family provided information to me about what others actually understood about disability. These early experiments were not intentional, but useful all the same, with my friends acting as signposts of understanding and awareness.

### Solidarity in Silence

My two sisters, engaged in similar experiments as we united to protect our family from cruelties that spawned from ignorance and lack of experience. Our complicity in these experiments did not evolve out of an organized collusion but through an underground consciousness of shared experiences. We harbored the same unspoken fears, witnessed the same struggles, endured the same screams and cries, shared the same joys and triumphs, and were repeat victims of the same prejudices. We never actually talked about our collective experiences. The unspoken awareness that we each coveted our family story was enough to bind us together as a tight knit family unit, despite our personal differences. The history we shared forged our family culture, and as Charlton explained, “it is within the realm we call culture that we get our

bearings in life” (2000, p. 51). Our sense of personal and familial identity was intricately woven by our mutual family experiences.

### Silence Bred Isolation

Although my sisters and I had a sense of solidarity through our experiences, my parents’ experiences were born in isolation, as they made decisions with only each other to lean on, determining the appropriate avenues for solving problem issues and supporting my brother’s continuous development and learning. There were no clubs, support groups, nor collective knowing from which to draw strength. At the heart of their isolation was the secrecy that cloaked many family experiences of disability.

In one neighborhood in which we lived, my parents befriended another family, resulting in children playing at each other’s homes and our parents enjoying casual dinners together. Over time, my parents learned this family also had a child with a disability, who they had institutionalized at a young age. Although this couple knew my parents’ situation with my brother, they had chosen silence and avoidance over conversation and dialogue. Their silence speaks volumes about the fear and shame that pervaded our society in the 1960’s.

Today, many families have access to support groups, where families who live with similar circumstances can learn from and lean on one another, finding solace in camaraderie. The satisfaction, however, is short lived when we recognize the impenetrable barrier that continues to exist between families who live with disability and those who do not. This void, eroded by silence and secrecy, remains difficult to cross and contributes to the ongoing marginalization of family members.

### The Public Stare and Acts of Resistance

#### Shared Experiences

Although there exists multiple dimensions of disability, making each person’s experience unique, people with disabilities do share some forms of social oppression (Wendell, 2006), such as the public stare, or “the look.” I was reminded about the look recently when in Denver co-presenting at a conference with a college student with Down syndrome and his mother. The focus of our presentation was on creating inclusive campus communities. While dining with this family, I became painfully aware of the stares of others, causing memories of the stares from my own childhood to wash over me. I was reminded of the resentment I had felt as a child toward those who demonstrated their curiosity, fear, concern, disgust, sympathy, or empathy in public ways, and I was confronted with the reality that even with all the work done in the field of inclusive education and inclusive communities over the past several decades, not much had actually changed.

The fact remains, individuals with disabilities and their families are often subjected to the public stare. It is one of the burdens of disability exposing “individuals to inspection, interrogation, interpretation, and violation of privacy” (Couser, 2006, p. 400). Wendell (2006) contended that the stares are born out of fear, ignited by perceptions of suffering, and that this

fear runs deep within our culture. Yet, my brother, just as the young man I was presenting with, did not suffer from anything. He had a good quality of life with a loving family, gainful employment, interests that were supported, talents that were capitalized. He contributed to his family and the community in meaningful ways, and yet, his presence continued to be responded to with reticence, caution, avoidance, and curiosity:

“When we make people ‘Other,’ we group them together as the objects of *our* experience instead of regarding them as fellow *subjects* of experience with whom we might identify. If you are ‘Other’ to me, I see you primarily as symbolic of something else – usually, but not always, something I reject and fear and that I project on you” (Wendell, 2006, p. 251).

### Perpetuating Oppression

The fear exuded by others was oppressive to my family and to me. What we considered normal was shunned outside the family circle, exemplified through a simple stare. My parents adopted cultural scripts of sorts, providing rehearsed answers to fend off inquisitions, but my sisters and I demonstrated our own acts of resistance by staring back, enough to make the curiosity seeker uncomfortable and turn away. We wanted onlookers (rubber-neckers, lookie-loos) to know what it felt like, responding to our oppression by oppressing others, being complicit in the preservation of oppressive practices. The ‘othered’ space of the margins is a space of resistance (Fine, 1994) not acquiescence. As a family, we found ourselves in the position to fight back at times, lashing out at those who threatened or questioned our balanced family dynamics.

In a study I did with teenage girls who had been identified as having an emotional disturbance, I noted their acts of resistance against the societal, organizational, and interpersonal forms of power to which they were subjected (Jones, 2004). I explained how this form of power over another is devastating because it acts to perpetuate the marginalization and oppression of others, similar to Willis’ (1977) *lads*. Years later, as I reflect on my personal history, I am just now beginning to recognize my own oppressive responses to the oppression I was feeling as a child because of perceptions others had of my brother’s disability, and question the connection these have to the personal and professional choices I make today.

### Raised Consciousness

For me, the history of societal marginalization seeps deeply in my skin and penetrates my being, as my family confronted injustices both in solitude and in a sisterhood of solidarity. Whether threatening not to join the neighborhood game of kick-the-can unless our brother could play too, or making others uncomfortable through our own version of the public stare, the intent was the same – to stop the behavior that was causing us discomfort, and to cause discomfort in others. Charlton (2000) spent ten years studying about and with individuals with disabilities who became disability rights activists. Through countless interviews, he noted how each respondent shared anecdotes of experiences that spurred the replacement of a “false consciousness of self-pity and helplessness with the raised consciousness of dignity, anger, and empowerment” (Charlton, 2000, p.16). This evolution of identity does not seem to be just a reality for

individuals with disabilities, but also perhaps for those fortunate enough to be around them such as peers and family members. At least this was the case for us. Hall (1991) noted that history influences our sense of self, and that our identities are partly generated through the relationship one has with an Other. “Only when there is an Other can you know who you are” (Hall, 1991, p.16). The cultural responses to which we were subjected seeded our rebellious reactions. It was our way to show pride and demonstrate value for what we held dear, negating the derogatory and demeaning views imposed by others through self-righteous indignation and action.

## The Message Behind Segregation and Isolation

### Historical Testaments to Injustice

The picture is of a small class of students, huddled together on the front steps of a school building, each squinting in the sun for the benefit of the photographer. Bookended by two teachers, the tiny band of students remains frozen in black, white, and shades of gray. This is a snapshot of historical significance because it is a snapshot of segregation and exclusion. The photograph hangs framed on the wall of my office, a testament to my family history, struggles, and beliefs, and acts as a reminder of why I make the professional and personal choices I do. It is why I feel I always have to fight for, explain, or support something, and ignites my passion for confronting practices of exclusion and ignorance, because seated on the front steps of the school among this band of isolated students, is my big brother.

The school is segregated. My sisters and I never shared the same teachers as my brother, did not learn the same subject matter, and did not cover the same curriculum. We did not share the experience of participating in school or community sports, theatre, music or art. This picture signifies a historical practice that occurred in my lifetime, when children with moderate to severe disabilities were exempt from a public education.

In the 1960s and early 1970s, compulsory schooling was only for those who could learn the three R's. The message sent by the exemption status was that children with more significant disabilities were not worthy of public dollars, and that it would be a waste of anyone's time to try to educate them. A perfect example occurred when we were living in California for a few months before my father's transfer to Connecticut.

### History Repeats Itself, Even in One Lifetime

I hold an indelible memory of my brother perched on a boulder at the end of our driveway waiting for us each day as we got off the school bus. Since we did not intend to stay in California long, it was easier for my parents to have my brother stay home during that time than it was for them to tackle the arduous task of finding a school that would accept him. When we moved to Connecticut in the mid sixties, and then eventually to Ohio in the early seventies, the scene was continuously repeated like a bad re-run, as my brother stood by the window and watched his sisters go off to school, college and jobs, living independently and away from home, and having opportunities that were not afforded to him.

On this last move, the school district in which my mom enrolled us recommended a sheltered workshop in another county for my brother, who was sixteen at the time. The workshop, a dismal place with insufficient work for the “clients,” employed managers with limited experience. When my brother, who was only able to speak a few words, refused to go, my mother, through some investigation on her own learned that when no work was available, clients had to sit at tables with their heads down. She simply stopped taking him to the workshop, and to my knowledge, no one from the school system or workshop setting ever came looking for my brother or ask for his return. Thus was the end to his formal education.

The educational inclusion of individuals with intellectual disabilities has been confronted with strong resistance over the last century. In her historical account, Winzer (2002) described the blatant fear of the “feeble-minded,” with eugenics advocates arguing for the institutionalization and sterilization of children with mental retardation, keeping students with significant disabilities out of public schools. Even with the push for increased educational opportunities for children with disabilities, “schools made it clear that they did not want trainables” (Winzer, 2002, p. 330), with institutions remaining the obvious option.

Although federal compulsory education laws were eventually enacted, multiple state rulings supported the continued exemption of students with more severe disabilities from attendance in public schools (Yell, Rogers, & Rogers, 1998). As recently as 1969, state courts “upheld legislation that excluded students whom school officials judged would not benefit from public education or who might be disruptive to other students” (p. 220), adopting the “all children except those” policies prevalent of the time. Progress was slow and hardly notable.

### Responses to Difference

With the signing of P.L. 94-142, the Education for All Handicapped Children Act of 1975, children with disabilities were all at once guaranteed the right to an education. While too late for my brother who had quit the sheltered workshop around 1973, this law was intended to open doors for others. Although this law and subsequent reauthorizations, mandated compulsory education for all children, there continues to be a segment of the school-age population that often remains ostracized and segregated from the public school environment through the use of segregated classrooms and separate schools. When I ask the preservice teachers and teachers in my classes where the students with moderate to severe intellectual disabilities are educated in their districts, I often receive the response, “We don’t have them in our school.”

As Sapon-Shevin explains, “Exclusion is not about difference; it is about our responses to difference” (2001, p.26). Entrenched in the minds of many of my current graduate students who support the learning of students with intellectual disabilities, is the perceived need to segregate their students. Instead of recognizing what benefit students might gain from interacting with others who do not have disabilities, educators continue to focus on the differences among students as primary considerations related to inclusion. Constricted notions of ability and learning potential mask a student’s value to a community, with society failing to recognize that learning is limitless regardless of perceived ability. While the use of terms such as “idiotic”, “imbecile” and “moron” are frowned upon in contemporary society, what society understands about the abilities and competence of individuals with intellectual disabilities remains stagnant,

with any budding awareness derived out of politically correct responses and not a true valuing of difference.

We need to raise our cultural consciousness to unveil the hidden assumptions about individuals with intellectual disabilities that foster exclusion. If we can rupture these tightly held beliefs, then we may be able to move beyond seeing disability as a “condition people have, but instead a social negation serving powerful ideological commitments and political aims” (Connor, Gabel, Gallagher, & Morton, 2008, p. 441). In contrast to segregation, inclusive classrooms can create the space in which students learn to take a stance against oppression, recognizing their own agency and power to make substantive changes (Sapon-Shevin, 1999), leaving a legacy of equality in their wake.

## Notions of Incompetence

### The Creation of Artificial Identities

In 1954, doctors told my parents my brother would never roll over, never crawl, and never walk. They were told to institutionalize him before they became too attached, because watching him suffer would only break their hearts. In this instance of medical sympathy, disability became synonymous with incompetence. Through conceptualized notions generated by those deemed abled and competent (Charlton, 2000), a social stigma prevailed over reality, creating an artificial identity for my brother and an undesirable (if not unfathomable) fate for my parents. Ferri (2008) called for a challenge of “reductionist understandings of disability” (p. 499) such as these, unpacking notions of incompetence and disability, providing competing frameworks through which others can view ability as a means for changing the disability paradigm in the United States.

I witnessed these competing frameworks every day growing up, as I was constantly reminded of not only my brother’s abilities and interests, but also of his character. He was honest, loyal, nurturing, independent, curious, mechanical, industrious, and musical, among other things, hardly the terms traditionally used to describe someone with an intellectual disability. As his sister, I resisted the notion of him being defined by his limitations because those did not seem to be the prevailing characteristics of his being. What was so difficult to witness and continually confront was the myopic view others had of him, focusing only on the areas in which he might need support instead of what he could meaningfully offer in return.

### Competence Versus Incompetence

Competence, as defined by Jenkins (1999), is “the capacity or potential for adequate functioning-in-context as a socialised human” (p. 1). If competence represents a socialized humanity, then incompetence must refer to a lack of humanity. The characteristics differentiating competence and incompetence are constructs that are contextually varied across era, setting, and culture (Jenkins, 1999), generating a composite of human variation to colonize people in to homogenous groups that are not homogeneous at all. Our cultural conceptions and interpretations of [in]competence, personhood and identity, profoundly affect the way in which people ultimately come to understand, relate to and treat people with an intellectual disability

(Edgerton, 1993). It will require a careful deconstruction of these cultural practices in order to eradicate them.

The idea of incompetence in disability proliferates from the accepted notions of normal. As Davis (2006a) contended, “The ‘problem’ is not the person with disabilities; the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled person” (p. 3). What is considered an allowable human variation of universal traits is produced by a “hegemony of normalcy” (Davis, 2006a, p. 4), with concepts of normal and the abnormal continuously reinforced in public ways. Within each society, variations exist as to what constitutes normal, but “at what point does this variation become disability?” (Wendell, 2006, p. 245). While much of the Disability Studies literature focuses on concepts of an idealized body, as a society we also idealize a concept of intelligence that inhibits our ability to embrace and value intellectual diversity.

### Challenging Paradigms.

Throughout my life, I never felt the sense of loss some parents describe when they learn their child has a disability, probably because I never envisioned my brother as broken or less than. The loss I felt was only in his death. This belief in parity among siblings became fully apparent to me during his funeral, when someone commented that at least Tom would not be disabled in heaven. I remember thinking, “Why not?” There was nothing wrong with him in the first place. If there was a God, would she/he have to change Tom before permitting his entrance through the pearly gates? I recognized then, in a state of awakening, that something was inherently wrong with this form of reasoning offered by a sympathetic friend.

Disability is “itself an unstable category” (Davis, 2006b, p. 237), revealing the absurdity of corraling individuals with disabilities in to artificial groups. Labeling individuals with intellectual disabilities as incompetent and less than is an arbitrary categorization of heterogeneous people, creating false subjectivities. Instead of sharing these patterns of thought we need to shatter them, moving away from degenerative toward regenerative beliefs about ability.

### From Pathology to Equality: Moving Beyond Difference

#### Advocating for Social Change

This essay was meant to be generative, moving beyond self-reflection toward a social change in perception, doing what Garland-Thompson (2006) suggests, unmasking and reimaging disability “not only for people with disabilities but for everyone” (p. 259). In our family, we were all subjects of care and oppression, as well as givers of care and oppression, creating a balance across birth order, gender roles, and perceived ability. Disability was not as apparent within the confines of our home as it was outside the walls of our house, supporting the perspective of disability as a social phenomenon, congruent to the perspective of Disability Studies scholars and activists (Conner, Gabel, Gallagher, & Morton, 2008; Gable & Danforth, 2008; Simmons, Blackmore & Bayliss, 2008; & Terzi, 2004).

## Family Cultures of Disability

While I remain unclear about the parameters of a disability culture, per se, as Brown (2002) contended, I am fairly certain there exists family cultures of disability. Although my parents practiced inclusion in our family before the term was ever coined, the world around us taught us about separation, perceived inferiority, and exclusion. My parents quietly fought the fight as they diligently demonstrated to us all that each person deserves to be loved, to be included, and to be a part of something. Through their actions, they also taught us that each person deserves the opportunity to have a dream and to follow that dream, creating an environment in which their children could all find success.

## Learning to Think Differently

Whether oppression comes from an Other as Russell (1994) promoted, or promulgated within systems of structures, as Charlton (2000) described, the end result is the same. Disability remains a fundamental aspect of human diversity and is an “inescapable element of human existence and experience” (Couser, 2006, p. 399), not to be ignored, isolated, or devalued. Helping others to recognize this fact is a painfully slow process, with awareness secreted among small pockets of informed and self-determined individuals. What we need is what Eiesland referred to as “cultural resymbolization” (1994, p. 98), producing counter images that alter the way we think about and imagine disability in order for radical social changes to unfold.

I disagree with Wendell’s (2006) call to abandon the term *differently abled*. In fact, I think it is how we should describe all of us, as we are each differently abled from each other, with variations of strength, talent, gifts, and interests. The error is in using the term only to describe individuals with perceived disabilities as we, as a society, continue to try to create pathology for our human variations. Acknowledging these variations instead of fearing them is an important step to a progressive cultural consciousness that recognizes and finds comfort in the fact that we are simply different...and simply the same.

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