

VOICES : on difference

A student-led journal focusing on issues of social justice



150TH CELEBRATION ISSUE

VOICES

VOLUME VI • ISSUE II • FEBRUARY 2022

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EDITOR'S NOTES

Thank You for joining us for the second installment of the West Chester University 150th Anniversary Issue as we explore Voices from past and present. Our writer's take you on a journey of self-reflection, policy exploration and the influence of societal constructs on our identity. The essay entries encourage us to assess how our lives are shaped by environment, community and policy-including imposed labels on our sexual and gender identity, or the titles imposed by the government like "welfare queens" can have detrimental effects on our development. Social workers and those in the helping profession use person first language to affirm our clients and service user's identity. The personal accounts in this installment bring to light the effects of degrading language and ineffective policy and behavior across systems. As you read, the heart wrenching stories that members of our West Chester Community have shared in this issue, take a breath to acknowledge their resilience and your own because we all have overcome experiences shared and unshared bringing us to where we are today; for those experiences have given us the motivation to overcome the past and continuously prevail throughout life.

Enjoy the second installment of *Voices: On Difference.*

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Nevermore: The Raven Motel as Community Olivia laquinto

"I'm assuming you want that room by the hour?" My mother stared at him, her eyes welling up with tears, and she answered, "No, by the night." The man behind the desk smirked and handed her a card key. "You'll be in room 116."

"My mother, my brother, and I were all crammed into a double bed in a room that smelled like urine and vomit."

That first night, it was near impossible to get to sleep. My mother, my brother, and I were all crammed into a double bed in a room that smelled like urine and vomit. We could hear the people next door having loud sex, and while I knew what it was, my brother who was only 10 years old and unaware thought the woman next door needed an ambulance. Between moans from next door and my mother sobbing into her pillow, eventually, somehow, I fell asleep.

The Raven Motel is situated in Media, Pennsylvania—a small, quaint town with a lively main street and lots of well-manicured houses. At the edge of town are the motels. There are three motels total, and The Raven is the cheapest (and the "sketchiest") one. The Raven is where sex workers go by the hour, where pornography is filmed, and where couples go when they're having an affair. But The Raven is also something the owners never intended it to be. The Raven is a home and a community to those who have been displaced.

She was on the phone for a long time and I had no idea who she was talking to. She kept looking like she was holding back tears and her voice sounded choked up at times, but there wasn't much being said on her end. It wasn't until she was off the phone that we found out that we lost all of our belongings. When we were evicted from our home, we had nothing packed or prepared. We were still in denial even as the sheriff arrived. All of our belongings were packed away and put into a storage garage. We would pay approximately \$2000 per month to keep our things in the garages until we found a stable place to live. Well, we didn't have anywhere near \$2000 a month so after a few months the storage facility called my mom and told her that they were auctioning off all of our belongings. Anything that wasn't sold in the auction was thrown in the trash and sent to a landfill.

"But The Raven is also something the owners never intended it to be. The Raven is a home and a community to those who have been displaced."

The Raven is an environment in which people live, die, prosper, and fail. When you examine the rooms of people at The Raven, you realize first that they don't have much. The motel provides a mini fridge and a microwave, a television, a bathroom, and a bed. There is one green chair per room and that's it. You can tell a lot about people by what else they bring. Our motel room was filled with children's toys, cat toys, and a giant birdcage that housed my hermit crab. In Mike the Manager's room, you could find ceiling-high piles of newspapers that he hoarded, each one of them important to him for one reason or another.

Mike the Manager: I hated him at first. He had insinuated that my mother was a sex worker and tried to charge her by the hour. But once he realized that she was a displaced mother with two young children, he became one of our best friends. We told him about the foreclosure and how we lost everything we had ever owned. We told him of my mother's major depressive disorder and how hard that made it for her to persevere. Mike had the biggest heart. He gave us money for food and a week later he brought over a huge garbage bag full of old toys that he had found in someone's trash. He asked for nothing in return, and just liked to see us smile.

Mike's story was heartbreaking as well. Mike was severely mentally ill and had a hoarding problem. He was forced into inpatient care and when he was released, his family had abandoned him and wanted nothing to do with him. He was homeless in Philadelphia for a number of years and started using drugs. Finally, he found a job at The Raven and he decided not only to work there, but moved in upstairs. He had been living there for almost 20 years when we got there, and he had no plans of leaving. To him, The Raven was home.

The Raven is home to several different types of people, all of whom have been displaced. Some people, like my family, were there because the housing market crashed and we lost our homes to foreclosure. Some people had a mental illness and were just released from inpatient with nowhere to go. Others were substance dependents who left their families for a life getting high, and fewer were criminals on the run from the police. Criminals staved at The Raven because living there was like dissolving off the face of the Earth: as long as you use a fake name and pay with cash, nobody has to know who you really are, and nobody outside the community has to know you exist. For these displaced people, for people who had no place to go, The Raven was a sort of sanctuary. For those who were alone, The Raven meant family. Never was I alone when I was at The Raven. At school, I was a social outcast, but at home I was seen as something precious. Everyone made sure the children at The Raven were fed and clothed, even before themselves. Everyone wanted to take turns taking walks with the kids or playing

cards outside with them. Children brought joy to otherwise pretty depressed individuals, and in a way, they provided their own form of currency.

My mother struggled with major depressive disorder and borderline personality disorder. Needless to say, she wasn't always able to be the best mom to me, but The Raven always had a sort of "replacement." Mary was my first replacement mother. She would tell me about her daughters that she left behind and teach me how to do my hair and wear make-up. We would have movie nights and talk about clothes and boys. We would go on long walks through town and we had inside jokes. When Mary eventually moved out, we even visited her at her apartment where she taught me to cook breakfast foods. My second replacement mom was Debbie, who would always offer me a place to stay and blow off steam after a fight with my actual mom. This happened frequently (imagine being 16 and living within two feet of your mother one hundred percent of the time), so I became very close to Debbie and we laughed and laughed about nothing in particular and about our lives.

Like a family, we supported each other. Nobody wanted Lisa to be on heroin but we knew we couldn't stop her so we just took care of her as best we could without enabling her disease. My favorite memory is from the holidays, like Thanksgiving. We would all pool our money together to get some Boston Market food. We would make one of the beds and use it as a table, setting out all the food family style. We would all share food and talk and tell stories and just feel close to one another. It was truly a wholesome family experience and one that could not be replaced, even by the "real" family dinners I experience now.

The night was dark and the room was sweltering hot. None of us could sleep. That's when we heard it...a metallic rapping at the door to our room. It was late, who was knocking at this time? "Who is it?" My mom called. "Let me in, I've got a shovel," said a gravelly and unfamiliar voice. My mom leapt up from the bed and bolted the door locked. She told my brother and me to keep absolutely

laquinto, cont'd

quiet and absolutely still. She got out her phone and she called Gabe from upstairs. For a while, she whispered into the phone. My brother and I were terrified. Before we knew it, we heard a racket outside like a fight. We heard Gabe's voice with his heavy Bulgarian accent telling the man with the shovel to run off and leave us alone, for good. My mom and Gabe never told us who the man was, although they definitely knew. Although this was a scary event, I felt safe. For the first time in my life, there were people I could call for protection all around me.

When we were living at the house with our mother, we were always on the verge of being taken away by social services. Our house was a health hazard, and if anyone stepped foot into those deplorable conditions, my brother and I would be removed immediately. We couldn't let the cops in, even when we needed to, because they would be obligated to make some sort of report. So I always wanted people to stay away from my house, to leave my family alone, to let us suffer in silence. We couldn't trust the outside world because the outside world wouldn't approve of what went on behind that big white front door.

People at The Raven didn't trust the police for many reasons. A lot of them were criminals or drug addicts who didn't want to go to jail. The police criminalized the homeless so harshly that everyone was afraid of being picked up just for being outside. Children were not allowed, so we were always in hiding. There were not to be more than two people per room, and we had three, so there was even more reason to hide. We heard things that would shock the average person: forced botched abortions going on next-door, domestic violence-even in an emergency, we never once called the police. Instead we relied on Mike the Manager or Gabe to protect us. For a while, we were living next door to a pedophile who was hiding from the law and as much as we wanted so desperately to report him, we couldn't for fear of being taken away. We had to protect ourselves from danger. The Raven is a community constantly on high alert because it is not protected like the rest of the greater community

is. Because our lives were criminalized, we lived in fear and lived without safety.

"I heard your mom sits outside the bus station and cries, telling your pathetic story to strangers, begging for money. Now that's just fucking sad."

Someone at school said that to me. First of all, my mother did not sit outside the bus station telling our story to strangers. She would never tell anyone our story—she was so ashamed. Second, my mother would never beg for change. We got our food money by checking under counters and freezers at convenient stores and gas stations. Usually when people dropped change there they would just sweep it under and we could collect it and buy Ramen noodles. Third, we are not "fucking sad" by any means; we are a strong and powerful family that takes no shit, that survives.

The Raven, as a legitimate community, is constantly challenged by the way it is viewed by the greater community. The town of Media views The Raven as a scourge of society, and essentially criminalizes our lives and our lifestyles. The greater community of Media frequently bands together in an attempt to destroy The Raven and rid the town of "those people" who live there. At one point, it was debated whether living there was legal at all. In 2007, politicians in Media were voting on whether or not it should be legal to live in motels like The Raven. As long as we paid the money each month, who cares how long we stayed? The people of the town saw it differently though. While living at The Raven, my high school told me I could no longer attend. Luckily, the McKinney-Vento Homeless Assistance Act said that I could attend, because living in a motel is still technically considered homeless, and because homeless youth can always attend their native schools no matter where they are "living" (U.S. Department of Education, 2004).

The Raven is a community categorized by shame. The shame is different for everyone, but the general shame of being looked down upon by the greater community is shame enough. For my mother, the shame was much worse. She was ashamed to have lost her home to foreclosure, she was ashamed to be mentally ill, and most of all, she was ashamed to say that she had her children living in some fleabag motel. I think a lot of people at The Raven feel shame. They feel shame when people from greater Media talk about them in the streets like they are less than human. They feel shame when they can't afford to buy food. They feel shame when they steal fruit from the grocery store. They feel shame when they can't take care of their children. They feel shame when they have an outburst or an episode in public.

At The Raven, shame seemed to melt away. It was as though shame only existed in the outside world. For example, when we were out and about in Media, everyone knew us as "the motel kids" and there was some shame attached to that because we were thought to be poor, dirty, low-lives. School was the same way. But at The Raven, we were home and the shame would dissipate like steam after a hot shower. We could share our stories there without receiving pity. We could be ourselves without being judged. We were a big family that supported each other and there was just no need for shame in a family as big and as love-rich as ours. I can say with certainty that The Raven saved my life. Without it, I would have been a homeless youth, sleeping outside on the streets with my family. I would have had absolutely no ties to a community or to anything greater than myself. The Raven gave me a home and a family and an identity. It became a part of who I was and who I would become. I would never shed my past and get rid of it like my mother (understandably) wanted to. Even if we left The Raven, it would still be home.

Most of all, I want people to know that The Raven is not a place of perpetual hurt and sadness, terror and crime. Just because the people at The Raven were poor and disadvantaged, marginalized and outcast did not mean that we were a bad community. We had strong values and dedication to each other, to ourselves, and to a way of life. We had unbelievable strength and resilience and we showed it every day just by surviving. If anything, our community was made stronger by our problems because we solved them or managed them together, as one cohesive whole. The Raven is not a place to be condemned, but a place where love grows and people flourish.

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Let Them Eat. . . Nothing ~ Sally Eberhardt

For many people of conscience and people facing poverty across the United States, autumn 2013 marked a new all-time low in the relentless, devastating cuts to federal assistance that have followed in the continuing aftermath of the 2008 global financial collapse. In November, federal food stamp benefits in the United States were cut by \$5 billion dollars for the upcoming fiscal year. Beyond providing crucial help to those who lack sufficient financial resources to feed themselves, food stamps often play a critical role in a life of nutrition versus a life of malnutrition. Political analyst Gary Younge (2013) argues that these cuts have nothing to do with offering genuine solutions to the fiscal crisis and everything to do with an ongoing ideological battle against poor Americans. Considering what budget cuts have looked like since 2008, this argument not only appears to be sharply accurate, it also points towards what looks like a continuing trend ahead in US politics. The most vulnerable in society are

made to bear the brunt of the global recession and capitalism's excesses (for one local example, see Amanda Hough's Philadelphia public school "crisis" piece on Page 12), while massive tax breaks and concessions continue to be doled out to corporations and the "1%" so that they can keep amassing what are now historic levels of profits and personal

wealth. Of course, thinking back over the past three decades, this "current trend" is actually nothing new as we can easily recall media spins and policy initiatives on both sides of the aisle that heaped capitalism's damage control on those at the bottom of the economic scale: Ronald Reagan's infamous and paradigm-shifting "welfare queens" PR campaign and Bill Clinton's shameful "welfare reform" are just two that spring to mind. The difference now is the heightened nature of the equation, most notably the unconscionable levels of corporate "wealth" (others, including the current Pope and other religious leaders, would likely use the word "greed") that we are witnessing.

In 2012, Charles Munger, vice-chairman of US billionaire Warren Buffet's Berkshire Hathaway company, made national headlines when he argued the United States was doing right when it bailed out Wall Street and let poor Americans take on the burden of budget cuts: "There's a danger in just shoveling out money to people who say, 'My life is a little harder than it used to be.' At a certain place you've got to say to the people, 'Suck it in and cope, buddy. Suck it in and cope" (quoted in Younge, 2013). One wonders exactly what Munger means when he uses the word "cope."

Following the 2008 collapse and the havoc it wrecked, food stamp use in the United States exploded – from just over 26 million recipients in 2007 to almost 47 million in 2012, an astonishing increase of 77% (Resnikoff, 2013). Even more arresting: nearly half the recipients are children (Sevenson & Hu, 2013). Current government figures indicate that one in seven Americans is food insecure and, according to an August 2013 Gallup poll, one in five Americans said that they have, at times during the past year, lacked money to buy food that they or their families needed (Younge, 2013). Harrowing data like this indicates poor Americans have indeed been "sucking it in" - and then some – for the past six years at the same moment corporate wealth has skyrocketed. Recent headlines from even the most zealous of corporate media including the Wall Street Journal and Forbes Magazine provide a powerful shorthand for this persistent state of affairs: "1-in-3 People Experienced Poverty From 2009

to 2011" (Wall Street Journal, January 7, 2014); "The 85 Richest People In "We are killing the poor The World Have As Much Wealth As The 3.5 Billion Poorest" (Forbes, in the many other ways January 23, 2014); and "Goldman: that social workers know Corporate Profits Grew Five Times Faster Than Wages in 2013" (Businessweek, January 24, 2014). Younge cites Marcia Potts' powerful September 2013 American

> *Prospect* article about rising mortality rates amongst poor and working-class white American women, noting in plain language what must be understood by all those working with poor communities in the United States: "Lack of access to education, medical care, good wages, and healthy food isn't just leaving the worst-off Americans behind. It's killing them."

all too well."

Delving deeper into the ideological campaign behind "austerity" politics, Younge recalls comments made by Republican Paul Ryan (who is currently trying to cultivate himself as anti-poverty crusader) in March 2012 about his own welfare philosophy: "We don't want to turn the safety net into a hammock that lulls ablebodied people into lives of dependency and complacency. That drains them of their will and their incentive to make the most of their lives." As Younge notes, currently 40% of households using food stamps have at least one person working, piercing through ideological mumbo jumbo about dependency and complacency. One could easily argue here that Ryan should be applying his dictum not to poor Americans who are trying to supplement unlivable wages so that they can feed themselves and their children, but instead to the banks that have been bailed out by taxpayers and

the multinational corporations that continue to receive head-spinning tax breaks. And of course, more than four decades of neoliberalism's carving away at real wages have also taken their enormous toll; as news reports and national studies continue to show, we are living in a world where median wages have consistently plummeted at the same time top corporate earners and corporation profits have soared. And yet, somehow, the response to this ever-growing imbalance has continued to be to attack programs for poor and working-poor Americans.

In 1980, at the start of what we can now look back on as the dawn of the frightening new era of neoliberalism spearheaded by Ronald Reagan and British Prime Minister Margaret Thatcher, the West Coast punk band The Dead Kennedys penned the dark, deeply satirical song "Kill the Poor" and sang – with eerie prescience – about a world in which conservatives and liberals alike (note the reference to Jane Fonda) united around the basic principle that the poor would have to bear the brunt of economic "austerity" measures and the rich (and those who aspired to be "the rich") gleefully took power into their own hands in order to eradicate the problems of the welfare state:

The sun beams down on a brand new day

No more welfare tax to pay

Unsightly slums gone up in flashing light

Jobless millions whisked away

At last we have more room to play

All systems go to kill the poor tonight

Kill kill kill kill kill the poor tonight

Behold the sparkle of champagne

The crime rate's gone

Feel free again

O' life's a dream with you, Miss Lily White

Jane Fonda on the screen today

Convinced the liberals it's okay

So let's get dressed and dance away the night

Kill kill kill kill the poor tonight.

While the armed guards of the rich may not be shooting the disenfranchised in the streets (and given the trend of police shootings of alleged suspects and "stand your ground" murders over the past six years, one could reasonably argue this point), we are killing the poor in the many other ways that social workers know all too well: food stamp cuts, unlivable wages, foreclosures, substandard medical care, and the many other cuts to federal assistance we have seen in action. Kill the poor? You don't need guns to do it, just a strong neoliberal ideology that can do the work for you.

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5

The suggestion that I don't know my own sexual orientation, and that I find it difficult to believe that anyone can, is not meant to imply evidence of personal unawareness nor is it meant to put into question our experience of authentic love and attraction.

What I *am* suggesting is that we only know who and what we are in relationship to our social constructs (Freire, 1997), which have the power to both restrict and release, con-fine and create. We also 'orient' within a domain of oppressive factors that determine the roles of gender and significance of skin pigment, which are most certainly dynamics that influence appeal, opportunity, and plausibility. What really throws flesh onto the bones of these concepts for me is Alice Walker's *The Color Purple* and the feelings Celie has toward Shug.

When my declaration of no true sense of sexual identity confuses people, angers them, I ask them to think of The Color Purple. It seems that most of my friends are quickly able to mentally assemble Celie's story. She is a

poor, uneducated, abandoned, black woman living in a small, racist, patriarchal world. It is dreadful. She is beaten and raped and relentlessly told of her awkward appearance. She is oppression personified. Shug, on the other hand, represents another idea of womanhood. Shug is different and Celie loves her. Is Celie gay? I contend that Celie, under such stark tyranny, was only able to self-actualize under the umbrella of othersactualized. The image of Celie's reality is often able to better illustrate my purposeful declaration of sexual complexity than any stories of my own. Oppression, when made so overt, is something that most obviously blurs the lines of self-realization. This point is mentioned in Miller's "Domination and Subordination" (2010) but more accurately explored in the first chapter of Pedagogy of the Oppressed (Freire, 1997). Celie's identity, even when liberated, remains a relation-

al response to the oppressor(s). Though her story of oppression is quite severe in its dehumanization, it should not give allowances for a multitude of oppressive factors to flourish in society simply because they pale in comparison. The more subtle social restrictions we face pose a threat in their cunning abil-

ity to often go unrecognized, untouched, and unstopped. Celie wonders, "Why us suffer. Why us black. Why us men and women" (Walker, 1982). These "whys," by nature, command the loss of self.

I may not live in a world like Celie's, but I do live in a world with Celie. We all do. For some of us, it is oppression not realized. For others of us, it is oppression ignored. Our attempts to 'identify' as one thing or another in such conditions are simply social responses to a socially constructed reality. In order to promote equality and gauge injustice, we are forced to use measures that categorize—an appropriate social response ironic in its necessity. Documenting racial distribution, for instance, may assist in promoting diversity, but our means of measuring fall short of capturing our true identity as a human community. Many of us find this difficult because race, in actuality, is a social creation. Navarro (2010) eloquently documented this in the article, "Going Beyond Black and White, Hispanics in Census Pick 'Other."" I deem that sexual orientation, like race, is also a socially constructed idea that doesn't really "fit" who

"I deem that sexual orientation, like race, is also a socially constructed idea that doesn't really 'fit' who we are as sexual beings."

we are as sexual beings and my opinion echoes much of what is addressed in Hubbard's "The Social Construction of Sexuality" (2010).

Although not everyone experiences difficulty with "fitting" or "not fitting" in racial categories, many can at least identify with those that do have such a dilemma. If asked to consider every person in the world and draw six lines (or 600 lines) of racial separation, most, I imagine, would have great difficulty with the task, both logistically and ethically. As Navarro (2010) pointed out, racial identity is not a simple question of a belonging or not belonging. Options for the best match are often ill fitting and a blending of choices frequently leaves more questions than answers. Sexual orientation, on the other hand, seemingly fits neatly into four categories; these suggest that you are *one*, the *other*, *both*, or *none*. This concept is likened to racial identity in "Night to His

> Day': The Social Construction of Gender" (Lorber, 2010). They all stem from the *one* and therefore are arguably exclusive, overly simplistic, and collectively inaccurate.

While Hubbard (2010) pointed to this concept in eloquent academic language, I find that I often have to defend a similar position about the

social constructs of gender and sexual labels in language befitting scenes more *social* in nature—like the barstools of Southwest Philly. I find that what is typically argued is that racial categories aren't really reasonable because, in addition to unique individual physical features, there are lots and lots and lots of colors. However, there are only two sets of genitalia: male and female. Thus, most conclude, there can only be two genders and *only that many* sexual orientations. There are lots and lots and lots of colors? Really? I thought it was just one color with lots and lots and lots of demonstration.

I don't like to say I'm heterosexual because, well ... I'm not—nor do I care to declare myself as homosexual. While it may honor my current same-sex relationship and give way to a justice-oriented political agenda, it also painfully denies tender memories of my past romantic relationships with men – very good men. Bisexuality doesn't seem an accurate description either, as it suggests that there is some kind of middle-ground, gobetween identity that denies the difference in how I am attracted to women and men. I am attracted to both, but not in the same way, and bisexuality seems to reject the idea of this unique disparity-something that I feel strongly. I sometimes am encouraged to make analogies to defend my sense of sexual orientation being "other" than options typically provided. I often make the comparison to dry ice (CO_2) by drawing attention to a scar on my right hand and pointing out the irony of the burn caused by a cooling agent. It is a compound that is both hot and cold, but certainly not lukewarm. Like the carbon dioxide compound, I am both heterosexual and homosexual, but do not fit as bisexual. I am both, but not both. I am all, but not other. My sexuality does not fit on a scale somewhere between 32° and 212° of attraction. Like CO₂, I am comprised of simple, common elements, but am unique in my composition. I believe we all are.

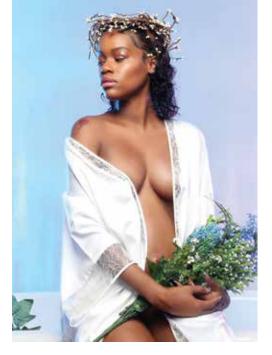
We live in a world of similar chemical compounds and our elements of identity are being fused together and broken apart in a bath of passionately charged movements: androcentrism battling gynocentrism, justice confronting injustice, civil rights defeating heterosexism, integration overcoming racism. I declare that I have difficulty separating Celie from the tyranny of her environment, I have difficulty separating myself from my world and the constant motion with which it moves. What I can say, with absolute certainty, is that I love my girlfriend. Her name is Maeve.

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Through the Looking Glass:

A PARENT'S PERSPECTIVE ON NEONATAL AND PERINATAL PREGNANCY LOSS



Cathy Plaisted, MSW Candidate '11

I remember that hot day in August so well. From the Braxton Hicks contractions, to wondering if my water had really broken, it was all so ordinary, for a first- time mom. I packed my bag and waved goodbye to my neighbors, all of whom assured me that I would probably be back home in a few hours. "Four weeks early? No way! False labor is common for a first-time mom."

Except, in my case it wasn't.

The doctor confirmed that my water had broken, and I labored for hours. My baby had fetal distress. I was rushed into the OR at 4 A.M. and given an emergency C-section. I gave birth to a 4 lb., 15 oz. baby girl named Grace. She was a healthy, pretty, brown-eyed baby with eyes just like her dad's. I was in love with her immediately and completely.

At 4 P.M., the nurses told me that Grace was having a hard time keeping her body temperature stable. "Normal," I was reassured by the nurse, and a quick trip to the Neonatal Intensive Care Unit (NICU) would be just that. Except, it was the last time I held my daughter without tubes and wires attached all over her body, unless you count when she died. My Grace had three heart defects that her ultrasounds could not detect. She survived two open-heart surgeries, but died from an infection acquired during her recovery. She was 30 days old; she was my first baby, and I loved her. I felt as if my heart had been pulled out of me.

Grace's time in the hospital taught me a lot, but mostly that "ordinary" and "normal" don't really matter much to you when you are the exception to the norm. It did not matter at the cemetery to know that other babies had died too. I just felt alone and sad. Family and friends stood by me, but I felt like no one understood. People kept saying that I could have another baby, but all I wanted was to have my baby, my Grace, back in my arms. I missed her so much and I cried more than I could ever imagine possible.

They say when you lose your parents, you lose the past; when you lose your friends or partner, you lose the present. But when you lose a child—you lose the future. If your spouse dies before you, society considers you to be a widow or widower. If your parents predecease you, society considers you to be an orphan. But if your child dies first there is no word to define your status. The closest words we have are "bereaved parents." But what if that child were an infant who died shortly after birth, a baby born still or who died during pregnancy? Then the language becomes even more difficult to understand.

These are the words we use to describe the loss of a pregnancy and or an infant: miscarriage, stillbirth, SIDS, abortion, neonatal demise. These are medical terms which sometimes are used to describe the death of a baby before or after birth, but more often, we will hear of a situation in which a family has experienced this and simply say that they "lost the baby." Every time I hear this expression, I have to suppress a wry smile. I imagine all the parents out there who would be so relieved to find the baby right next to a lone earring, several mis- matched socks, the appointment card from the dentist, or the spare set of car keys. What a relief! There she was all the time....

I facilitate a parent support group for pregnancy and neonatal loss. I do this because I believe in the power of groups and because my parent grief support group held me up through the darkest hours of my life. But I

really do this to honor my baby girl and because I know that the power of telling your story leads to healing. At every support group meeting parents share their story of their baby as a part of the introduction. Typically, it is very hard to share details of your baby's birth with people you know well, let alone people you do not know at all—especially because the ending is so sad. But I have found in our groups that just being in the presence of others who have experienced a similar situation makes this easier. Sometimes parents will not want to speak at all, but listening to others' stories opens up your heart as well as your mind.

The most common themes I have learned are the following:

- There is diversity in experience. Some people wanted these pregnancies, some may have been ambivalent. Others may not have wanted another baby at all. Ask us if we want to talk about it—it's okay. We have already suffered enough and your silence may only add to our hurt.
- Parents may feel isolated and ashamed of their loss as if it is their fault. They may feel that they could have prevented the loss, even though this is not true. We need to be careful with the language we use—no one is to blame.
- Listen to our story. Ask us about our babies. Learn their names. They were a part of our families. Show us you care—we are struggling. We need you to care, but we may feel uncomfortable asking for help. This is especially true after a few months have passed since the loss and it seems everyone has forgotten.
- Show support for siblings. They may not understand why the baby died and may feel guilty as well. Their parents are grieving, so siblings may need extra sup- port and comfort. Please let them know it is not their fault.
- Finally, please do not assume that the loss of a pregnancy through miscarriage is somehow easier than losing a full term pregnancy. Every pregnancy loss is uniquely personal and has meaning.

CULTURAL INCOMPETENCE IN THE HEALTH CARE SYSTEM

by Colleen Keeler

andra's parents thought they had planned for everything before she was born. They read dozens of parenting books, arranged for childcare, and created a beautiful nursery, shelves lined with all the essentials. However, no amount of stocking closets could have prepared them for the words that were about to leave her doctor's mouth: "Your daughter has sickle cell disease."

A dozen questions flooded their minds—is she going to be okay? How do we treat this? What is her life going to look like now? Sensing their terror, the doctor assured them that while incurable, her sickle cell disease could be managed as long as Sandra adhered to the doctor's recommendations and returned to the hospital for frequent clinic visits. She made it sound so easy, yet they were overwhelmed and deeply afraid. Her parents lamented to each other, "How can we possibly afford to take time off of work for so many appointments? And what if she needs to be admitted to the hospital?" Although they each worked multiple jobs, it was difficult to keep food on the table and clothes on their backs. Despite their concerns, they collected as much information as they could from the doctor and headed home, determined to give their daughter the best life possible.

For a while, everything seemed to be okay. Sandra's growth was a bit stunted, but she hit all her milestones and made lots of friends. When she was 4, Sandra experienced a sickle cell crisis that sent her to the hospital. As always, her parents went to Sandra's doctor for advice, asking, "What can we do to prevent this from happening again?" Nonchalantly, the doctor responded, "Easy! Just provide her with a more nutrient-dense diet, filled with plenty of vegetables and healthy fats. That's one simple way to improve her symptoms." But Sandra's parents could not easily afford these foods, and even if they could, there wasn't a single grocery store in their neighborhood that kept them stocked, so Sandra's diet remained the same. When Sandra's doctor assumed that her family had the resources to make these changes, she failed to take into consideration the environmental factors that prevented her family from managing her disease in the ways that were recommended. If she had considered the sociocultural and economic characteristics that created barriers for Sandra, she could have worked with her parents to develop a more feasible plan for improving her symptoms.

When she was a teenager, Sandra's doctor suggested she start taking a medication called hydroxyurea to manage her symptoms. Her family declined, indicating that they felt alternative remedies would be more effective in managing Sandra's pain. "We actually prefer to use traditional medicine and were hoping to find an herbal remedy to help ease her pain." This frustrated her doctor, who quickly dismissed this suggestion. "That has no scientific backing," she told them sternly, adding, "Doctors know best. You need to stick with what research shows is the best treatment." Instead of providing them with all of the information and allowing them to make their own choices about Sandra's treatment, her doctor insisted that there was no room for flexibility. After repeatedly being told that they didn't know what was best for their daughter, Sandra's parents developed a distrust for medical providers and started taking her to fewer appointments, dreading the judgment that accompanied each visit.

As she grew older and began braving these appointments on her own, Sandra's negative experiences with health care providers were amplified by the stereotypes that they began to associate her with-they assumed she wouldn't follow through on treatment recommendations, that she felt pain less intensely than her white counterparts, and that any pain medicine she did receive would be abused rather than taken as prescribed. She once came into the emergency room with debilitating sickle cell pain and sat in agony for hours just waiting to be seen. Finally, she was called back to see a nurse. "I have sickle cell disease and I'm having a pain crisis. My pain is at a 9," she quickly informed them. The nurse pushed back, stating, "I'm sure it's not that bad. I see you've come in quite a few times for pain, and I'm not comfortable giving you medicine that you might abuse. You'll be fine with some ibuprofen."

Sandra's is not a unique case. This phenomenon is commonly experienced by African Americans, with one survey indicating that 25% of medical students believe African Americans don't feel pain as much as white people, the implications of which are prolific (O'Neal, 2019). Not only are they frequently prescribed less pain medication than a white person with the same level of pain would receive, but their pain is often dismissed, causing them to suffer unnecessarily, and in the worst cases, leading doctors to miss important warning signs of life-threatening conditions. One striking example of this is that of professional tennis player Serena Williams, who experienced severe complications following the birth of her daughter in 2017. When she felt short of breath, Serena, who had a history of blood clots, immediately recognized that she might be having another pulmonary embolism. She told a nurse right away that she needed a CT scan and a blood thinner, but the nurse disregarded her, stating that the pain medicine might be making her confused (Haskell, 2018). Despite being a wealthy, world-renowned athlete, medical providers still assumed that her pain was not a cause for concern simply because she is Black. Further, this differential treatment is not exclusive to treating pain-research indicates that at least two-thirds of health care providers hold some type of implicit bias against marginalized groups (Merino, 2018).

Culture does not exist within a vacuum: it informs our interactions with the world and those around us. Communication, which Martin (2010) describes as occurring when someone attributes meaning to someone else's words or actions, is inextricably linked to culture in that it is ultimately our cultural values that inform our perceptions of reality, and thus, the meanings we attach to others' words or actions. As such, we are unable communicate effectively if we fail to consider the vastly different behaviors, attitudes, and values practiced by different cultures. In some cases, this leads to nothing more than a simple misunderstanding between two people. In others, it can lead to large disparities between entire populations.

This lack of cultural humility runs rampant in the United States health care system. Health data shows that African Americans have a lower life expectancy, a higher death rate, and higher prevalence rates of diabetes, hypertension, heart disease, and stroke than whites (Byrd & Clayton, 2000). Many of these health outcomes can be addressed by shifting our focus toward a model of health care delivery that encourages cultural humility. While this may sound simple in theory, the fact that dramatic health disparities still exist shows us that health care institutions in the United States continue to exclude culture when informing models for best practice. It is imperative for doctors to educate themselves on the specific treatments being utilized by families like Sandra's so that they can effectively and respectfully treat patients from cultures unlike their own. It is important to note that a balance can be struck between respecting a service user's choice and still disagreeing with that choice; while a doctor does not have to recommend a treatment that they find ineffective, they still have a duty to familiarize themselves with such treatments so that they can better understand their patients' perspectives. In addition to staying informed, medical providers must examine and address their own implicit and explicit biases on a constant basis to ensure that they are providing the same treatment to all of their patients.

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Contributors

Sally Eberhardt MA, MSW, received a BA in English and Philosophy at Fordham University and an MA in English (Literary History and Cultural Discourse) from the University of Sussex in the UK before earning her MSW at WCU. Sally came to Social Work after almost two decades of working in the field of international justice and human rights work as a researcher, writer, and documentary film producer. Building on this professional experience and activist work that has included anti-war campaigning and organizing with economic and social rights movements, Sally brings an activist sensibility into her work as a geriatric social worker.

Robert Graves, MSW Candidate '22, is a recipient of The Philadelphia MSW Cohort Scholarship. He has a professional background in advocacy, education, behavioral and mental health services and program development. He is also a multidisciplinary visual and performing artist, curating advocacy documentaries, art shows and short films. Throughout his enrollment in the MSW program he has served as Graduate Assistant at the PASSHE Student Success Center and as a student evaluator on the Newcombe Scholarship Committee.

Olivia laquinto graduated with her MSW in 2016 and is now working as a school-based therapist for The Center for Child Development in Delaware. Olivia hopes to make a difference for children experiencing significant life stressors or trauma.

Colleen Keeler graduated from the WCU MSW Program in May 2021. During her time at WCU, she worked as a research assistant, conducting studies in the areas of harm reduction, LGBTQIA+ issues, and more. In her final year, she also served as Vice President (WC Campus) of the Phi Alpha Honor Society and was a recipient of the HRSA BHWET Grant. Colleen went on to receive her LSW and currently works as a Care Coordinator at Lankenau Medical Center, where she remains committed to patient-centered integrated care. **Bridget McGovern** is the Social Work Manger for Children's Hospital of Philadelphia (CHOP), Primary Care Network. She supervises social workers as well as community health workers and is involved in many projects related to program development and evaluation. Before her current role, she was the Social Work Operations Lead in CHOP's Emergency Department. Bridget is a licensed social worker who received her Master of Social Work from West Chester University in 2014. She has been working in social services for more than 20 years, primarily in behavioral health and quality management. Bridget was certified in Ecosystemic Structural Family Therapy in 2013 and appreciates integrated approaches to behavioral health treatment. She is a proud Southwest/West Philadelphia native who now lives with her wife, foster son, and beagle in South Philly.

Cathy Plaisted WCU MSW Class of 2011, is currently working as a Primary Care Social worker at the Coatesville VA. She works in Geriatric Primary Care and in the Whole Health Pain Clinic in addition to general primary care. Cathy has diverse experience working with individuals and families across the lifespan in a variety of settings including child welfare, family court, schools, hospice care, primary care and in home health care. Cathy has worked with Unite, Inc for over 20 years to provide cost-free grief support for individuals and families who have experienced miscarriage, perinatal loss and infant loss. She also is the proud mom of two rainbow children (babies born to a family after surviving a previous loss of another baby through miscarriage, stillbirth, or infant death.)

