

## MEDICINE AND SOCIETY

### What Do Unusual Faces Teach Us About the Ethics of Recognition?

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#### Abstract

With close attention to the film *Wonder*, this article examines how a narrative of community acceptance offers sustaining relationships for people with unusual facial appearance. This article argues that premodern responses of wonder can help reframe modern understandings of looking different.

#### Responses to Unusual Faces

In his practical advice book, *Changing Faces: The Challenge of Facial Disfigurement*, James Partridge gently but insistently counsels people with newly acquired facial injuries about how to manage other people, a task that Partridge suggests is more demanding than managing one's own facial injuries.<sup>1</sup> Of concerned friends and family, Partridge advises, "They have usually come to help you, but you may well find that you have to help them."<sup>1</sup> Of the many visual interlocutors one must face out in the world, Partridge concludes, "One secret of changing faces is to realize that *you* have to help them to break out of their scared-ness and meet you face-to-face."<sup>1</sup> Partridge's instruction manual lays out the social agency that patients must cultivate in order to achieve a quality of life that can be equal to that expected for people without disabilities. His insight into the work of what medicine considers [rehabilitation](#)—and what psychology considers adjustment for people with disabilities—comes from his own experience of living with an unusual facial appearance.

The 2017 film *Wonder* complements Partridge's practical wisdom for people with unusual faces by portraying how a 10-year-old boy with Treacher Collins Syndrome develops the social and life management skills that I call *dignity maintenance*.<sup>2</sup> *Wonder* is at once an extended case study in managing unusual facial appearance and a *bildungsroman* detailing how the fledgling hero ripens from a callow child into a mature young man equipped with the self-knowledge, direction, and worldly wisdom to lead a good and moral life. *Wonder* offers transplant recipients a lesson both in how to manage social relations while maintaining their dignity and in how to conceptualize the [acceptance and recognition](#) they need to rebuild a sense of [self-value](#). The story thus offers a model for how people with unusual appearances can cultivate interdependent relationships and high quality of life.

### **Managing Others' Perceptions**

In *Wonder*, Auggie Pullman, whose rare genetic condition and 27 surgeries have given him a very unusual face, enters school for the first time in fifth grade after being homeschooled by his devoted mother. After the shock of his birth, Auggie's family has come to love him—as many parents of children born with disabilities affirm in their memoirs<sup>3,4,5</sup>—because he is theirs and his distinctiveness makes him the son they love. We, like Auggie, are loved not for our normality—which is a statistical composite that no one actually fully embodies—but rather for our particularity. Sheltered and supported by his loving and economically secure family, Auggie has accrued the essential inner resources to become a sturdy and secure person. Inside his family circle, he is an ordinary kid playing games, teasing his sister, and sharing his day with his parents. Upon entering the community of peers at school, however, he is subjected to rejections that he has never before needed to navigate. He must endure rude stares, curiosity, bullying, and every kind of unwanted attention a kid as different as Auggie must endure. Up until he enters fifth grade, Auggie, who loves science and space travel, always has gone out of his home wearing an astronaut helmet that conceals what geneticists term a “coarse” appearance in which the proportions, shape, and placement of his features—riven now with scars from multiple surgeries—diverge far from ordinariness. Auggie gives up that astronaut helmet as he leaves the sheltered familiarity of his family and enters a community of anonymous peers.

Like Partridge's newly facially injured advisees, Auggie must learn to help his peers accept his extraordinary appearance. He must learn to take control of his own narrative, to help others understand his uniqueness as valued rather than damaged. As his older sister, Via, wisely advises him after the first day of school, “You can't blend in when you were born to stand out.” Through his experience of entering into the school community of peers and teachers, Auggie ultimately learns the social skills that sociologists call *stigma management*<sup>6</sup> by developing his own distinctiveness, by welcoming the attention that his singular appearance provokes, and by understanding his face as the emblem of his unique Auggieness. In other words, Auggie learns to cultivate in others outside his family circle the emotional response of *wonder*, the awe people feel when they witness something they've never seen before. He does this by persisting in presenting his unusual appearance as part of his distinct self rather than hiding behind the astronaut helmet or in the safe space of his family who recognize and love him as he is.

### **Reframing Unusual Appearance**

*Wonder*, Auggie's *bildungsroman* suggests, can be a productive, even redemptive, frame through which people with significant appearance impairments can be understood, accepted, and appreciated in today's modern social world. *Wonder* is an affect that was elicited in response to phenomena in the natural world that were rare—even singular—and often taken to be omens or divine signs during the premodern period. Large-scale dramatic phenomena such as earthquakes, comets, or similar inexplicable and

unexpected visitations provoked wonder, understood as a psycho-emotional state of awe that brought together terror and fascination, a version of what the Romantics called the *sublime*.<sup>7,8</sup> Prodigies, divination, oracles, soothsayers, shamans, and all manner of worship rituals gained social traction from their power to inspire wonder. Ancient wonders such as the star of Bethlehem and the Cyclops Polyphemus, as well as hybrids such as Pegasus, Minotaurs, or angels are still prevalent in our received cultural archive. Early modern cultures of collection such as the cabinets of curiosity or the precursors to our contemporary museums harnessed the power of wonder by shifting communal rituals focused on singular objects or occurrences to private ownership of powerful objects that drew intense attention and speculative interpretation.<sup>9,10,11,12</sup> Human wonders such as so-called monstrous births, which we now understand as congenitally disabled newborns, as well as singular embodiments or the kinds of bodily shapes that could be interpreted as hybrids of animals and humans, were prized as occasions for prophecy or worship. A newborn with a face like Auggie's arriving in the premodern world—like other rare physiological forms such as conjoined twins, cycloptic stillborns, the hirsute, babies with fewer or more than the ordinary 10 fingers, or all manner of what now counts as abnormality—would have elicited wonder as a form of intense attentiveness from which meaning—revelation of a curse, blessing, transgression, election, or some other form of singularity—could be drawn and then debated.

The development of science with its systems of classification and measurement brought wonders down to earth and out of the realm of mystery and superstition. The very qualities of rarity and singularity that made the wide range of natural, animal, or human wonders culturally valuable and venerated in premodern cultures are the qualities that the modern system of medical science deems *abnormal* and aims to eliminate. Modernity disenchant the wonder, transforming the narrative of the marvelous into a narrative of the deviant.<sup>13,14</sup> As modernity develops in Western culture, the prodigious monster becomes the pathological specimen; what was once a revelation becomes a birth defect; what aroused awe now inspires horror; what was once to be valued is now to be cured. But wonders endure in modern societies as what cognitive scientists call *novel stimuli*, unfamiliar or rare phenomena that draw attention and interest. Even while societies value predictability, expect regularity, and extol the normal as a desired achievement, the power of human singularity endures, and wonder can be invoked as a stigma management strategy for people with a facial appearance like Auggie's.<sup>15</sup>

### **Stigma Management**

When Auggie went out into the world hiding his face behind his astronaut helmet, he was exercising what the conversation analyst Harvey Sacks calls "doing being ordinary" and what the sociologist Erving Goffman describes as seeking civil disattention.<sup>16,17</sup> In modern anonymous communities whose size extends beyond a knowable kinship circle, being ordinary is the social benefit of avoiding undue attention from or being interrupted by the unknown others who constantly surround us. Auggie must leave that helmet with

his father when he enters the schoolyard, where his peers stare at and torment him. Auggie's story of development begins as he literally shows his peers who he is: his distinctive self that is made up of his knowledge of science, his astronaut costume on Halloween, his kindness, his humor, his limitations—and his unusual face. After the first day of school, he cries to his mother, "Why do I have to be so ugly?" But day after day of presenting his face to the outside world of other kids transforms him from ugly to wondrous in their eyes, distinctively Auggie. At first, his radically unusual face was unreadable to his peers as anything else but ugly. But as Auggie's particular persona emerged day after day, his face came to be understood by the other kids as not so much ordinary as familiar—as the face of their friend and classmate, unusual and extraordinary as it was. He became one of them, and his face became the emblem of his distinctiveness. He amazed them and was—quite literally—*awesome*, not because his face was so strange but because he was the person they had come to care about.

The disability rights lawyer, activist, and storyteller Harriet McBryde Johnson, a person with an unusual appearance, offers a story about social management strategies for helping people move from seeing her as ugly to seeing her as wondrous. "It's not that I'm ugly," she writes in the *New York Times Magazine* in 2003, "It's more that most people don't know how to look at me."<sup>18</sup> "Two or three times in my life," Johnson continues, her distinctive appearance has evoked the response of wonder, an appreciation for what she calls "a rare kind of beauty ... some people call me Good Luck Lady: they consider it propitious to cross my path when a hurricane is coming and to kiss my head just before voting day."<sup>18</sup> This sense of his own "rare kind of beauty" is what Auggie learns to recognize and accept, not only within the safe haven of his family circle but also in the community of peers at school.

The film's final scene narrates interpersonal validation as recognizing and appreciating the distinctive "rare kind of beauty" of people with unusual and highly stigmatized appearances. Sometime after Auggie has made a place for himself in the work and social environment of school, he asks his father about the long-missing astronaut helmet. Having hidden Auggie's helmet at his office, his father explains to his beloved son that when the boy started wearing the helmet, "I never got to see you anymore." In what I found the most moving moment in the film, Auggie's father says, "I missed your face." Acknowledging his son's own struggle, Auggie's father continues, "I know you don't always like it [your face], but I love it. It's my son's face. I want to see it." This affirmation of the distinctive, individual human face echoes the philosopher Emmanuel Levinas's premise that to regard the face of the other is the fundamental moral task of being human.<sup>19</sup> Auggie's face is beloved because it is different from every other face; it is the means through which his father knows his cherished son. Such a response that recognizes particularity is an example of the ancient affect of wonder, a cleaving to the strangeness of the other—here, of the other's face. To his father, Auggie's face can

never be ugly but is instead the face of Johnson's "rare kind of beauty," a beauty like no other.

At the end of his life, dying from cancer, the neurologist Oliver Sacks published a series of essays reflecting on the experience of dying and the wisdom it brought him. A lifetime observer of the human condition, Sacks concluded that the essence of being human is our distinctiveness. "When people die, they cannot be replaced." Sacks, our time's most important observer of wonder, wrote, "They leave holes that cannot be filled, for it is the fate—the genetic and neural fate—of every human being to be a unique individual, to find his own path, to live his own life, to die his own death."<sup>20</sup> For Sacks, our human distinctiveness is a source of wonder. That all human uniqueness, perhaps especially that which is unusual or rare, can evoke wonder is what gives meaning to our lives and the work of being human. This is what Auggie has learned when he tells his father he doesn't really need to find that astronaut helmet after all.

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