

Advocacy for Persons with Facial Disfigurement: A Tribute to Dr. James Partridge (1952 – 2020)

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James Partridge was a professional hero and friend of mine who died unexpectedly this summer. For decades he was a tireless advocate for the equitable treatment of persons with facial disfigurement. While much of his work involved collaborations with medical and mental health professionals, his work to understand the experience of stigma and discrimination among those with facial disfigurement, and then advocate for equitable treatment, serves as a model of how to use personal experience and research evidence to advocate for positive change at the population level.

James's work was personal. When he was 18 years old and preparing for his first year at Oxford University, he was involved in a horrible automobile accident. As he describes in his book *Face It: Facial Disfigurement and My Fight for Face Equality*, published in the summer of 2020 (<https://jamespartridge.wordpress.com/>), the life-changing event left him with severe burns and scars to much of his face and body. The book provides a detailed description of his surgical and medical care in the first few years after the accident. James brings us into his social world for those years, sharing his hopes and fears about being accepted by others. Pictures of his injuries are paired with equally intimate reflections about his process of accepting his changed appearance. James mourns his former appearance while framing his candid admissions of his hopes and fears in the context of stigma theory. As a mental health professional who has worked with persons with visible disfigurement for 25 years, I learned countless, new lessons from James' narrative.

I first met James in 1997. I was a newly minted Assistant Professor at the University of Pennsylvania and was asked to give a talk on facial disfigurement to the annual meeting of the Phoenix Society for Burn Survivors (<https://www.phoenix-society.org/>). At the conclusion of my talk, a tall man in the back stood up and said "You said that very little is known about the psychological issues of facial disfigurement. Actually, I lead a group in England called Changing Faces and that's all we do. You need to be better prepared and know what is happening outside of the States." I was speechless and embarrassed as I had never heard of Changing Faces and their work; most of the work on physical appearance in the United States had been focused on social advantages experienced by very attractive individuals. Few researchers in America were studying the psychosocial issues challenges of those who were disfigured.

I mumbled something of an answer in response and quickly fielded another question. The session mercifully ended soon after. I had been publicly humiliated and now wanted to give that guy, James, a piece of my mind. He was in the back of the room talking to a few people. As I walked closer, I could see the scars on his face for the first time. My anger began to dissipate but I still wanted to tell him I

didn't like how he embarrassed me. I stuck out my hand and introduced myself. He did the same and then said, "Sorry if I was a little hard on you there. People know I can be direct. My organization, Changing Faces, is doing important work on these issues in England." I was completely disarmed. I also was charmed as James projected so much confidence as he spoke. I witnessed firsthand what he describes in the book; James forced himself to develop social skills that allow him to create interpersonal interactions that are comfortable for him and others.

In the years to come, James and I communicated regularly. I also become close colleagues with his collaborators at the Centre for Appearance Research at the University of the West of England in Bristol (<https://www1.uwe.ac.uk/hls/research/appearanceresearch.aspx>). The Centre is home to the largest group of mental health professionals working on appearance and disfigurement in the world. I was honored by those colleagues in 2014 when they invited me to serve as a keynote speaker at their biannual Appearance Matters meeting. I encourage readers to view the video highlights from the conference to see the passion that James felt for his work (beginning approximately 1 minute into Conference Film 2; <https://www1.uwe.ac.uk/hls/research/appearanceresearch/newsandeventsfrom/appearancemattersconference/historyofappearancematters/appearancematters6.aspx>).

Under James's leadership, Changing Faces became a very successful charity in England (<https://www.changingfaces.org.uk/>). The group worked with the British government on a number of initiatives, including the Disability Discrimination Act of 1995 and 2010 Equality Act, both of which included facial disfigurement as conditions protected under discrimination law. Notable also was the promotional campaign, largely seen on bus stops throughout England, which had images of persons with disfigurement and accompanying text which debunked many of the stereotypes people have about them. Over the past few years, James focused his energies on a new charitable initiative called Face Equity International (<https://faceequityinternational.org/>). He wanted this group to have more of an international focus. As he shared this vision with me, I was excited about the possibility that we could partner on the project and that I could use my background on the psychology of appearance and my new position in Temple University's College of Public Health to help the organization flourish in the United States.

On Sunday August 16th, I read about James's unexpected passing on Twitter. I was shocked and saddened but also oddly comforted by the fact that I had recently received his latest book, which featured a fantastic picture of James's face on the cover. It was wonderful to learn more about my friend's life through his memoir—both the details of his challenges but also his many successes. The second half of the book, where James details the history of Changing Faces and his dreams for Face Equity International, is a primer on how to engage in effective advocacy for your personal or professional passion, which were one and the same for James. The lessons for public health professionals, regardless of discipline, are endless.

Since James's death, I've learned that one of his favorite sayings was "On, on". It is a simple reminder of how James faced the challenge of his life; the saying also a gift from James to us from James as it reminds us to keep our work, and ourselves, moving forward. Rest in peace, my courageous friend. Your friends and colleagues will "on, on" with the fight for equitable treatment for those who are disfigured in tribute to you.

Disclosures and Conflicts of Interest

Dr. Sarwer declares that there is no conflict of interest.

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