

Disability and Shame Special Issue Forum: Introduction

Disability and Shame

Stephanie Patterson, MLS

Stony Brook University

Dana Lee Baker, PhD

California State University Channel Islands

John Y. Jones, PhD

Truman State University

In July 2016, a man entered the Tsukui Lily Garden in suburban Tokyo in the middle of the night and stabbed over 40 people. Nineteen died. The Tsukui Lily Garden specializes in caring for adults with cognitive impairments. Satoshi Uematsu, a former employee of the facility, turned himself in to the police shortly thereafter and confessed his crime. "It is better that disabled people," he told them, "disappear."

When one of the editors of this series, John Jones, expressed his dismay about the attack on the listserv of the *Review of Disability Studies: An International Journal*, he noted in the local response to the tragedy a reflection of Japanese culture: after the attack, many of the victims' family members did not want it publicly known that one of their loved ones was involved.¹ The requests for anonymity, and in some cases flat refusals of acknowledgment, were grounded in the shame that would attach to the families who had relatives residing at the Tsukui Lily Garden. Shortly after sharing his thoughts, the *Review of Disability Studies Journal* reached out with a suggestion to initiate a special forum on the topic of shame and disability. This issue is the result of that suggestion.

Shame, like any human emotion, finds expression in a number of ways. Moreover, manifestations of shame are tempered by a wide range of factors, from the broader culture of the person or persons experiencing shame to the microcultures of the person's family dynamics and immediate social milieu, as well as the source of the shame itself. This special forum addresses this last point: disability and its relationship to shame.

For this issue, we sought as broad a range of scholarly perspectives as possible and we were not disappointed. The goal was to include a wide selection of international views and diverse disability experiences. The articles that follow examine the intersection of shame and disability through a variety of frameworks. Articles discussing the complexity of shame in East Asia and the Middle East share space with intimate first-person narratives grounded in ethnographic scholarship. Some articles are broad and theoretical, others offer a more practical perspective. Submissions focus on the effect of shame not only on the disabled individual, but on families, as well. Together, all showcase a rich diversity of ongoing scholarship in a field deserving our full attention.

Embracing a broad range of perspectives includes acknowledging differences in contemporary preferences regarding the language of disability. Toward the end of the

twentieth century a majority of disability scholars and advocates encouraged use of person-first language. A core explanation for this preference asserted that because the fundamental humanity of people with disability had long been denied and ignored, those wishing to contribute to the end of ableism should acknowledge the person before any difference in capacity relevant to their experiences. By the turn of the twenty-first century, the dominance of person-first language became so pervasive that many scholarly journals and public agencies around the globe required its use.

Even as the popularity of person-first language rose, some hesitated to transition from traditional language forms which lists disability as a primary characteristic of the individual in question. Others found the person-first language unnecessarily cumbersome. Finally, and most importantly, some disability activists stressed that the differences in capacity called disabilities played so central a role in their identity that disability (or identity) first-language was not only preferable but the only truly appropriate language form given a goal of respecting diverse identities.

Debate remains regarding disability language. Given that disability reflects interaction between capacity and infrastructures and that contemporary identities are multifaceted, personal language preferences vary across time, spaces, and interactions. In order to work most positively and proactively with the topic of shame, the following articles contain authors' own language choices.

We begin our special forum with “The Intersections of Culture, Disability, and Shame: The Experiences of Emerging Adults with Developmental Disabilities and their Families in South Korea” by Mina Chun and Diana Ferguson. This article examines how culture and shame effect the lives of 12 families of adolescents with developmental disability. “Three Dimensions in the Register of Shame” by Jean-Pierre Tabin, Monika Piecek, Célin Perrin and Isabelle Probst follows—an article that discusses the effects of shame on disabled recipients of Social Security benefits in Switzerland.

“The Cultural and Religious Production of Disability Shame and the Saving Power of Heretical Bodies” by Michelle Mary Lelwica continues the discussion of the effects of shame created by cultural and religious beliefs about physical disability. In “Dealing with Shame: Saudi Mothers' Responses to their Children's Diagnosis of Autism Spectrum Disorder” by Mona Sulaimani and Dianne Gut, we return to the effect of disability shame on families, examining how the degree of parental shame and stress is proportional to the severity of children's symptoms and behaviors.

“Mental Health Disabilities, Shame and the Family: The Good, the Bad, the Chosen, and the Imagined” by Cassandra Evans is an ethnographic research study exploring shame through the lens of mental health issues related to deinstitutionalization and community-based mental health care. And finally, we complete our forum with an article by Maggie Bartlett, “A Counter-Narrative to Shame in Namibia” evaluating her experiences interviewing families of disabled children in Namibia, Africa.

In an effort to expand our understanding of shame related to disability, in addition to our literary offerings, we are fortunate to include artistic expressions about the topic. We have works from artist Ann Millett-Gallant, illustrator Anna Faroghi, and poems from Lisa Boskovich and David Isaac Hernández-Saca.

The issue of shame coupled with the problems of ability and disability remain an area rich for future scholarship. The authors in this issue have invested an immense amount of work into the articles that follow. In many ways, however, the broader work is just getting started. We hope that this humble beginning will stimulate our readers to both think deeply about this pressing issue and consider examining the intersection of shame and disability in their own scholarship.

We are profoundly grateful to have had the opportunity to work with authors who have given so generously of themselves to this effort. We are also thankful to the editorial team at the Review of Disability Studies Journal for shepherding this project along.

We wish to close by noting that the subject of shame itself can be a depressing one to contemplate. When we consider the many manifestations of shame, most of which are less tragic than the killings in Tokyo but nonetheless painful for those experiencing them, despair sometimes follows. Our intention in compiling this series of articles is to provide a forum for discussion, raise insights, and share perspectives to help scholars and laypersons counter that despair and instead find reasons for optimism and hope. That so many scholars wanted to contribute their work to this issue gives us reason for great optimism, indeed.

Stephanie Patterson, MLS has expertise in the field of disability and employment as a result of integrated experiences in disability studies, higher education, disability services, career services, human resources, and labor relations. Some of her research endeavors include publishing her new book *Disability and Employment in the United States* with Cognella Inc., and co-editing a Special Forum on Disability and Employment in the Review of Disability Studies that highlighted her article entitled, “A Historical Overview of the History of Disability and Employment in the United States (1600–1950).” In 2014, she published a book chapter, “Working 9 to 5... or Not: Historical Origins of Disability Discrimination in the U.S. Workplace” for Piraeus Books.

Dana Lee Baker, PhD has expertise in disability policy, with emphasis on neurodiversity, neuroethics, and autism. Dana brings considerable experience as a peer reviewer from a number of scholarly journals such as *The Social Science Journal*, *Journal of Public Affairs Education*, *Journal of Public Policy Analysis and Management*, *Social Problems*, *Educational Policy Journal*, *Scandinavian Journal of Disability Research*, *Journal of Autism and Developmental Disabilities and Emotion, Space, and Society*. Dana has also served as an ad-hoc reviewer for the National Science Foundation and for the Social Sciences and Humanities Research Council of Canada. Dana edited a two-volume book series entitled *Disability and U.S. Politics: Participation, Policy, and Controversy*, published in 2017.

John Jones, PhD has expertise in disability policy with an emphasis on special education

policy, eugenics, and the history of special education. He has served as a reviewer for American Educational Research Association, the History of Education Society, and the American Library Association. He was invited to create this call for papers by the editorial staff of the *Review of Disability Studies: An International Journal*.

Endnotes

1. It should be noted that John Jones is himself of Japanese descent and that his parents and grandmother reside a few miles from the location of the attack.



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