

Society for the Study of Social Problems In Pursuit of Social Justice

Summer Issue July 2019

Division

Disability

Greetings from the Disability Division Co-Chairs

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Hello Disability Division Members!

We hope you are having a pleasant summer. We want to take this opportunity to provide you information on Disability Division news and Annual Meeting announcements!

We are pleased to report that Kate Caldwell will be our new 2019-2021 Division Co-Chair. For those of you who do not know Kate, you can learn more about her on page 11. Justine will continue as Co-Chair through 2020, and Scott will return to regular membership. Congratulations and Welcome to Kate!

We are also pleased to announce the results of a very competitive Graduate Student Paper Award competition. Congratulations to Dalton Stevens for his winning paper, "Stuck in transition with you: Rooting, returning, and in(ter) dependence for men with mobility impairments" (see page 12). As the competition this year was so close, we also awarded an Honorable Mention. Please join us in congratulating Melinda Maconi for her paper "More than Therapy: Conformity and Resistance in an Organizational Narrative of Disability and the Performing Arts" (see page 13). We appreciate all of the graduate students who submitted papers for the 2019 competition. The diversity and quality of the submissions was a real testament to the bright future of our Division. Help us congratulate Dalton at the Awards Ceremony on Saturday, August 10, 6:45pm-7:45pm, followed by the Division-Sponsored Reception 7:45-8:45pm. We will also recognize both papers at the Disability Division Business Meeting on Saturday, August 10, 10:30am-12:10pm.

Our Section members created a great line-up of Division Sponsored Sessions for this year's conference in New York (see pages 6-10). As always, these cover diverse topics of interest to disability scholars, with many cosponsored by other SSSP divisions of interest. We hope you will be able to join us for the insightful presentations and rich discussion that are a hallmark of our Division Sessions.

Justine will be leading the charge to begin planning the conference sessions for the 2020 SSSP Annual meeting in San Francisco. On page 16 you will find a description of her timeline for brainstorming and organizing these sessions. We hope you will volunteer to organize a session. It is a great way to ensure that research topics that interest you are on our program.

We look forward to seeing you in New York!

Scott and Justine

Disability division mission statement

The Disability Division is devoted to the critical study of disability in society, including the structural and sociocultural mechanisms through which disability is (re)produced and (re)constructed as an axis of oppression and exclusion. Our concerns are wide-ranging, and include the following:

1. Disability has historically been, and continues to be, overlooked within mainstream sociology. Disability remains understudied and undertheorized as both a phenomenological category of existence and a social category used to disqualify groups of people and deny them access to cultural, economic, and political resources.

2. The historical treatment of people with disabilities and associations of the label disability with disqualification and denial of full citizenship have resulted in a persistent pattern of differential outcomes in many areas, including: housing, income, education, civic participation, voting, incarceration, and self-determination.

3. Disability has emerged as a source of collective identity, around which people have formed multiple social movement organizations that advocate for greater inclusion and social justice for people with disabilities. The disability rights movement, the civil rights movement for people with disabilities, has engaged in significant and meaningful political activities – including nonviolent civil disobedience – as part of this struggle. Counted among their successes are: the enactment of the Rehabilitation Act (1973) and subsequent amendments, the passage of the Americans with Disabilities Act (1990), and the inclusion of the Community First Choice Option in the Affordable Care Act (2010).

4. In addition to advocating on behalf of their own community interests, people with disabilities have participated in and continue to participate in other social movements working in coalition for a more just world.

5. Ableism, like racism, sexism, ageism, heterosexism, other and institutional and structural forms of prejudice, discrimination. and marginalization, has a significant and pervasive force impacting the lives of everyone in society. Further interrogation is needed into the ideologies and practices that sustain ableism, as well as the immediate, intermediate, and cumulative effects of ableism on individuals, communities, and nations.

6. Historical and contemporary (re)presentations of disability and people with disabilities by the dominant, able-bodied culture have dehumanized people with disabilities and rejected their agency as producers of knowledge. As people with disabilities have come to critique and reject these other-made (re)presentations, new forms of disability culture(s) have emerged that (re)claim bodily and emotional performance and assert people with disabilities as experts on their own lives.

As a socio/politico/legal category, disability represents an important claim of citizenship on the State for resources, services, protection, and power. Conversely, the State is constantly engaged in renegotiating the boundaries of the category of disability in order to de-legitimate or mitigate these claims.

8. Environments influence and inform the experience of disability and disabling processes. Social, physical, natural, ideological, and geopolitical environments create unique contexts in which specific types of bodies and minds are validated and others are marginalized.

9. The recognition that disability is a social determinant of life opportunities and of health across the lifecourse. Disability shapes individuals' lives, just like more widely recognized determinants, such as gender, race, ethnicity, and class.

10. Members of the division are interested in how disability intersects with other social characteristics, including but not limited to, gender, race, ethnicity, class, sexual orientation, veteran and immigration status.

11. Our examination of disability as a social characteristic is grounded in social models of the phenomenon, which address segregation, institutional barriers, and discrimination. Although we do not ignore the body in our work, the primary focus is on how societies treat individuals with disabilities and the consequences of that treatment.

Our vision of a just world is one where all individuals are supported in their efforts to live to their highest potential in environments that enable opportunity and actively combat all forms of discrimination. Specifically, these environments would afford access for people with disabilities to meaningfully participate in schools and jobs, families, communities, and other social groupings. Our work is focused broadly and seriously addresses both the power of disability as a social category and the lives of people with disabilities and the contexts in which they live them.

Within our division, disability is recognized within the social problems framework. Disability is both something that individuals and groups in society produce (through war and work, for example) and construct (through ideas and representations). Consequently, disability is re-politicized, and the prevailing idea that disability is a personal problem is rejected.

Examples of some of the topics that our members have explored include: Disability policies, community activism and organization, the intersection of race and culture in the experience of disability, disability and war, the medical normalization of disability, and disability and life course.

Illuminating the SOCIAL in Social Problems

The Society for the Study of Social Problems 69th Annual Meeting August 9-11, 2019 Roosevelt Hotel New York City, NY

In his book, The Forest and the Trees: Sociology as Life, Practice, and Promise, the late Allan G. Johnson wrote that the most important thing sociology teaches us is that we are always participating in social systems



that are larger than ourselves. Because we are constantly shaping and being shaped by social systems, individualistic models do not work for understanding the social world or for solving social problems. Indeed, Johnson tells us that if we want to solve social problems, we need to understand, explain, and address what is "social" about those problems.

The theme for the 2019 SSSP meetings is a call for social justice theorists, empiricists, practitioners, activists, policy makers, and analysts, to draw deeply and widely on sociological teachings to illuminate the social in all aspects of social problems. If our founding scholars were correct, then our ability to illuminate the social in social problems will help solve some of the major social problems of our time.

The move away from individualistic models is critical in such an illumination. Individualist models focus on the characteristics of individuals without looking at the relationships that connect individuals to each other, to groups, or to larger society. Johnson reminds us that people do not exist outside of systems, and systems cannot function without people. And yet, "people are not systems, and systems are not people," but the relationship between the two is critical to understanding the social world and the problems caused by unequal power relationships institutionalized throughout history. In other words, a forest is not just a bunch of individual trees, but rather "a collection of trees that exist in a particular relation to one another." Similarly, society is not simply a collection of unrelated individuals, but rather a collection of people that exist in a particular relation to one another; and those relationships create the very essence of what is "social" in our lives. So when we illuminate the social in social problems, we are illuminating the patterned, structural, and institutionalized relationships that exist among us and connect us together to create our larger social world. Because of an increasing focus on individualistic models, public discourse lacks a social structural analysis regarding race, class, gender, sexuality, nationality, religion, mass incarceration, and immigration, to name a few. For the 2019 SSSP meetings, I call on our membership to reclaim and refocus that public discourse. Let us carefully consider the connective spaces between the trees that creates the larger forests; the spaces in which social problems are embedded and perpetuated by unequal power relationships. Let us push forward our disciplinary roots to explain what is social about social problems, so that what we understand to be obvious becomes obvious to everyone around us and becomes part of popular thought and parlance.

As a community of social science and social justice researchers, activists, and practitioners, I invite the SSSP membership to join together during the 2019 meetings in New York City to use our collective sociological imaginations to explore each corner of the social world. Our exploration should have the explicit and strategic intention of illuminating the social in social problems and applying what we study and practice in pursuit of becoming a more just global society.

While in New York City, explore this great urban forest as well. Go north on the Manhattan island to Harlem and see the birthplace of some of the greatest American culture. Travel to the southern part of the island and discover how Wall Street got its name. While there, find out where over 10,000 people of African descent were buried in the 1700s, or visit the areas where immigrants lived in tenement homes and started small businesses. Take a ferry to Ellis Island or Liberty Island. Stroll or bike through Central Park, walk the High Line, or visit any number of the green spaces in the City. Take a subway to Brooklyn to see Judy Chicago's "The Dinner Party." Travel to Greenwich Village and check out where a significant part of the modern LGBTQ movement began. And of course, take in the many shows and good eats that NYC has to offer. As you wander around, think about how the spaces of the City connect the seemingly separate neighborhoods and histories to create one large and complex city.

Just as the possibilities of exploring and connecting the many spaces in NYC are endless, so are the possibilities of exploring and connecting the endless spaces of the social world. And as NYC becomes a more illuminated city to you as you explore, let us use our expertise in August 2019 to help illuminate the social in social problems with an intention of informing the rest of the world.

Nancy J. Mezey, SSSP President Monmouth University



Disability Section Sessions

Session 006: Disability and the Arts

Date: Friday, August 9 Time: 8:30 AM - 10:10 AM Room: East End Suite Organizer & Presider: Sara E. Green, University of South Florida

Papers:

- "Exploring Non-normative Queer Embodiment through Sociology and Photography," Justine Egner, University of Wisconsin LaCrosse and Jesse J. Egner, Parsons School of Design at The New School
- "More Than Therapy: Conformity and Resistance in an Organizational Narrative of Disability and the Performing Arts," Melinda Leigh Maconi, University of South Florida, **Honorable Mention of the Disability Division's Student Paper Competition**
- "The Borderline Struggle: Humanizing Women with BPD," Jennie Lambert, Georgia State University
- "Whose Story, Whose Voice?: Helen Keller as Told through Children's Literature," Cheryl Najarian Souza, University of Massachusetts Lowell
- "Deaf Identity Salience: Tracing Daphne's Deaf Identity Salience through Switched at Birth," Penny Harvey, Georgia State University

Session 032: The Invisibility of Disability in Intersectional Approaches

Date: Friday, August 9 Time: 12:30 PM - 2:10 PM Room: Fifth Avenue Suite Sponsors: Disability, Racial and Ethnic Minorities Organizer & Presider: Laura Mauldin, University of Connecticut

Description: The papers in this session consider a variety or topics using a variety of methodologies, but all address the intersections of race, class and disability. By examining disability alongside race, class, and gender, these papers make a critical contribution the sociological literature on intersectionality.

- "College Campus Sexual Assault and Female Students with Disabilities," Margaret I. Campe, University of Kentucky
- "Bringing in the Black Body: An Phenomenological Examination of Acquired Physical Disabilities in Haiti," Kapriskie Seide, University of Miami
- "'Today, Wheelchair Riders at McDonalds': Racialized Construction of Disability Activism in a Grassroots Periodical of the 1980s," Matthew G. Borus, University of Chicago
- "Intellectual Disability, Educational Attainment, and Birth Cohort: An Intersectional Approach," Erin M. Bisesti and Scott Landes, Syracuse University
- "Disability, Race, and Language: Evaluating Access to Online Information about Assistive Technology in the US," Brian R. Grossman, Randa Abdelrahim, Yovia Xu, Ellyn McNamara and Angelica Martinez, University of Illinois at Chicago

Session 046: Disability and Relationships Across the Life Course

Date: Friday, August 9 Time: 2:30 PM - 4:10 PM Room: Riverside Suite Sponsors: Disability, Family, Youth, Aging, and the Life Course Organizer & Presider: J. Dalton Stevens, Syracuse University

Description: Disability is simultaneously a relational experience, identity, complex life course process, minority status, and form of oppression. This session is comprised of papers that explore disability and social relationships across the life course including papers focused on but not limited to family dynamics, partnering, sexuality, gender, friendships, social networks, employment, disability theory, identity, stigma, health care, education, and benefit program participation. This session intends to bring together a diverse array of papers focused on describing and explaining social relationships during different times in the life course experienced by people with disability. This area is historically underdeveloped, and this session addresses the gap in the disability and life course literature pertaining to barriers, facilitators, opportunities, and experiences of social relationships for those with disability.

Papers:

- "Earlier and Risk Free: New Approaches to Prenatal Screening and New Problems," Barbara Katz Rothman, The Graduate Center, CUNY
- "I Don't Do Well with Probabilities: Mothers' Stake-lowering Work with Cell-free DNA Prenatal Screening," Aleksa Owen, University of California, Berkeley
- "'Men Are from Mars and Women Are from Venus': The Erotic Habitus of Adults with Intellectual Disabilities in Ontario, Canada," Alan Santinele Martino, McMaster University
- "Stuck in Transition with You: Rooting, Returning, and Interdependence for Men with Mobility Impairments," J. Dalton Stevens, Syracuse University, Winner of the Disability Division's Student Paper Competition
- "Postponed Retirement Delays Cognitive Decline: Using Counterfactual Causal Inference to Disentangle Life-course Risk Factors for Later-life Cognitive Decline," Jo Mhairi Hale, University of St Andrews, Maarten J. Bijlsma and Angelo Lorenti, Max Planck Institute for Demographic Research

Session 089: Neurodivergency and Neurodiversity

Date: Saturday, August 10 Time: 12:30 PM - 2:10 PM Room: State Suite Sponsors: Disability, Society and Mental Health Organizer: Justine Egner, University of Wisconsin LaCrosse Presider & Discussant: Melinda Leigh Maconi, University of South Florida

- "Immobilizing the Moving Target: Bureaucratic Narrowing and Truncating of Mental Illness," Kerry M. Dobransky, James Madison University
- "Twice Isolated: An Exploration of the Experiences of Autistic Transgender Adults," Nicole A. Rios, The Graduate Center, CUNY
- "#ActuallyAutistic: Using Twitter to Construct Individual and Collective Identity Narratives," Justine Egner, University of Wisconsin LaCrosse

Session 102: Disability and Labor

Date: Saturday, August 10 Time: 2:30 PM - 4:10 PM Room: State Suite Sponsors: Disability, Institutional Ethnography, Labor Studies Organizers: Jennifer D. Brooks, Syracuse University, Doron Dorfman, Syracuse University Alison Fisher, York University Presider & Discussant: Jennifer D. Brooks, Syracuse University

Description: The relationship between disability and labor is complex and multidimensional. Disability can be viewed as both a discursive category, and as a social relation that is actively organized and coordinated through relations of power, similar to race, class, and gender. Thus, disability, as a social category, shapes how individuals both produce and consume labor. Structural and individuallevel barriers to the labor market participation of individuals with disabilities have led to their dramatic unemployment/underemployment rates. This lack of participation in the labor market has simultaneously resulted in and maintained the belief that individuals with disabilities are 'unfit' labor producers--furthering their occupational and social segregation. People with disabilities also rely on the labor produced by others (such as caregivers, personal assistants, family members, surrogate mothers, friends, partners, and others) to fully participate in social life. This type of labor is often unpaid and goes unrecognized. To examine the relationship between disability and labor, this session seeks papers that cover a wide range of topics including: the exploration of structural and individual-level barriers to labor market/economic participation, intersectionality, dilemmas related to consumption of labor, the unpaid/unrecognized nature of care work, workplace experiences (both of people with disabilities as employers and as employees), and how policies and texts* shape the experiences of people with disabilities as both labor producers and consumers. *We define text as both discourses (in the Foucaldian sense) and various other texts (collective agreements, codes of ethics, even mundane 'texts' such as bus schedules, computer interfaces, etc.).

- "Disabled and Poor in the Bay Area: How SSI and SSDI Beneficiaries Work around and within Current Labor Incentive Programs," Katie Savin, University of California, Berkeley
- "Implications of ADA Disability: Examining the Association between Functional Limitations, ADA Disability, and Labor Force Participation," Jennifer D. Brooks, Syracuse University
- "Public Disability Benefits as Harm Reduction: Income as Part of Complex Care Management," Ariana Thompson-Lastad, University of California, San Francisco, Mark D. Fleming, University of California, Berkeley and University of California, San Francisco, Meredith Van Natta, Duke University, Sara Rubin, University of California, San Francisco, Irene H. Yen, University of California, Merced and University of California, San Francisco, Janet K. Shim and Tessa M. Nápoles, University of California, San Francisco and Nancy J. Burke, University of California, Merced and University of California, San Francisco
- "Self-determination in Transportation: The Route to Social Inclusion for People with Disabilities," Jessica A. Murray, The Graduate Center, CUNY

THEMATIC

Session 126: Disability is Not the Problem: Moving Beyond the Social Model

Date: Sunday, August 11 Time: 8:30 AM - 10:10 AM Room: York Suite Sponsor: Disability Organizer & Presider: Brian R. Grossman, University of Illinois at Chicago

Papers:

- "'It Was Just This Liberation': The Acquisition of Disability Cultural Capital among Young Blind Adults," Angela Frederick, University of Texas at El Paso
- "'We Are Both Not Responsible and Wholly Responsible': Making Sense of Personal Experiences of Disruptive Chronic Illness in Light of Illness Identity Discourse," Hwa-Yen Huang, National Dong-Hwa University, Taiwan
- "Enhanced Psycho-social Intervention Improves Medicare Patient Mental Health Outcomes," William D. Cabin, Temple University and Susan Havens-Lang, Lang Associates
- "Suspicious Species: Assistance Animals and Visible Signs of Compliance," Doron Dorfman, Syracuse University
- "Disability, Health, and Human Development," Sophie Mitra, Fordham University

THEMATIC Session 137: Trans/Queer/Crip: Illuminating Bodyminds

Date: Sunday, August 11 Time: 10:30 AM - 12:10 PM Room: York Suite Sponsors: Disability, Sexual Behavior, Politics, and Communities Organizers: Katherine Caldwell, University of Illinois at Chicago Chris Wakefield, University of Nevada Presider: Chris Wakefield, University of Nevada Discussant: Katherine Caldwell, University of Illinois at Chicago

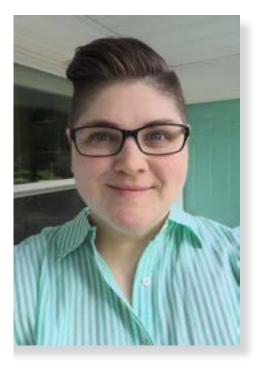
- "Breaking the Bi-nary: Illuminating In/visibility," Katherine Caldwell, University of Illinois at Chicago
- "Disability and Aging within the Bisexual Community," Lynette McFadzen, BiNet USA
- "Paying for Pleasure: Sex Work to Support Disabled Sexuality," Bethany Stevens, Georgia State University

Session 138: PAPERS IN THE ROUND: Disability - Inclusion, Access, and Rights

Date: Sunday, August 11 Time: 12:30 PM - 2:10 PM Room: Grand Ballroom Sponsor: Disability Organizer: Scott Landes, Syracuse University Roundtable #1 Title: Disability Presider: Justine Egner, University of Wisconsin LaCrosse

- "Disabling Discipline: A Quantitative Analysis of Over-disciplining Students with Learning Disabilities," Kimberly D. Tanner, The George Washington University
- "Disability Rights in Displacement: Critical Appraisal of Policies, Practices, and Issues," Alex Otieno, Arcadia University
- "A Mental Health Crisis? Changes in Mental Health and Treatment, 1997-2017," Amy L. Johnson, Stanford University
- "Selected Sexual and Reproductive Health Challenges of Disabled in School Adolescents in South West Nigeria," Macellina Yinyinade Ijadunola, Obafemi Awolowo University, Nigeria
- "Who Supports Red Flag Laws? Public Opinion about Laws to Remove Guns from Compromised Owners," Margaret S. Kelley, University of Kansas, Christopher G. Ellison and Pablo E. Gonzalez, University of Texas at San Antonio

Welcome to new division co-chair, Kate Caldwell!



Dr. Kate Caldwell is a theorist, methodologist, and empirical researcher whose work advances knowledge, policy, and practice on critical disability issues in employment, social policy, and poverty. Having received her Doctorate in Disability Studies from the University of Illinois at Chicago and Masters' degree from the University of Chicago in interdisciplinary social sciences, Dr. Caldwell brings this expertise to approaching complex issues where various fields intersect and facilitating dialogue across disciplines. Currently a Clinical Assistant Professor at UIC, she is known for her work situating intellectual disability within disability studies. One of the topics she is frequently asked to speak on is Dyadic Interviewing, in particular a method she developed for interviewing people with intellectual and developmental disabilities that holds great potential for advancing the way we think about research participation in the field. For two and a half years she served as the Editorial Coordinator

for the journal, *Intellectual and Developmental Disabilities*. During her postdoctoral research fellowship she conducted research evaluating the Ligas Consent Decree as well as developing and implementing a comprehensive evidence-based education and training program for entrepreneurs with disabilities (www.CEEDproject.org). Her research often uses entrepreneurship as a lens through which to look at different aspects of disability employment from poverty and un/under-employment to sub-minimum wage and disparities in leadership and advancement.

Dr. Caldwell served as a content expert for the National Task Force on Workforce Development and Employability for People with Disabilities, conducted in collaboration with the U.S. Department of Labor's Office of Disability Employment Policy (ODEP) State Exchange on Employment & Disability (SEED) initiative, along with the Council of State Governments (CSG), in partnership with the National Conference of State Legislatures (NCSL). In this capacity, she contributed to a report titled, "Work Matters: A Framework for States on Workforce Development for People with Disabilities," using research findings to develop policy recommendations that could be implemented at the State level through knowledge translation strategies. She has also served on the Chicago Mayoral Task Force on Employment and Economic Opportunity for People with Disabilities as Chair of the Priority 1 Working Group on Encouraging Economic Development through Entrepreneurship; and the Financial Advisory Council for the Empowerment of people with Disabilities (F.A.C.E.D), a joint effort by the Chicago MOPD and the City Treasurer's Office to break down barriers for the disability community as it relates to access to financial institutions, education, and services. Dr. Caldwell has recently received a grant to research leadership and women with disabilities in government over the course of the coming year, and will be a Co-Investigator on the upcoming Disability and Rehabilitation Research Project examining Entrepreneurship among Low-Income Youth with Disabilities with Drs. Parker Harris, Balcazar, and Renko.

Congratulations to Dalton Stevens, Graduate Student Paper Competition Winner!

"Stuck in Transition with You: Rooting, Returning, and Interdependence for Men with Mobility Impairments"

Abstract: More people born with disability are living to adulthood which has called attention to the transition to adulthood for this population. In the US context, overarching narratives of the transition to adulthood are underscored by a cultural value of independence, and these narratives are embedded in US policy dedicated to transition services for people with disability. However, actual experiences of the transition to adulthood among people with and without disability are more in line with interdependence considering the prolonged nature of intergenerational exchanges and delayed social transitions in the present context. Using life history interviewing techniques and ethnographic "go-alongs" with 9 men with mobility impairments analyzed with grounded theory methodology, the paper explores how participants experience and make sense of independent living and interdependence during the transition to adulthood. The narrative data reveal diverging pathways to interdependent living situations: rooting before transition and returning during transition. The pathways are shaped by unequal access to social capital that correspondingly encourage accessibility expectations or individual adaptability which have significant implications for independent living, assessments of interdependence, and possibly health. Together, these variable pathways indicate that some young people with disability reframe the importance of independent living in transitioning to adulthood while others maintain it as a relevant social marker of adulthood. Findings suggest transition services and Medicaid must cater to both groups in different ways, and encourage service providers to assess local housing stock's accessibility while preparing young adults with disability for independent living post-high school.



Dalton is a PhD student at Syracuse University (SU) and is affiliated with the SU Aging Studies Institute where he is working on various projects centered on disability over the life course. His dissertation uses a life course approach to understand how social relationships and structures shape the transition to adulthood for young people with disability, and "Stuck in Transition with You" is a precursor to the broader dissertation research, chaired by Professor Madonna Harrington Meyer. He is grateful to the SSSP Disability Division for selecting this paper for the 2019 Graduate Student Paper Award. He appreciates the division's and broader society's commitment to promoting graduate student paper awards as it fully integrates students into the

membership. He is also working on projects with various collaborators focused on mortality trends among those with intellectual disability, cerebral palsy, Down syndrome, and other developmental disabilities; Medicaid and disability; and the history of disability in sociology. Most recently, he coauthored "Obscuring effect of coding a developmental disability as the underlying cause of death on mortality trends for adults with developmental disability" with Professor Scott Landes and Dr. Peggy Turk which appears in Volume 9, Issue 2 of *BMJ: Open.*

Congratulations to Melinda Maconi, Graduate Student Paper Competition Honorable Mention!

"More than Therapy: Conformity and Resistance in an Organizational Narrative of Disability and the Performing Arts"

Abstract: Artists with disabilities use their bodies and minds to express themselves, perfect their craft, and create art. However, despite the legacies of many talented artists with disabilities, art programs for people with disabilities are consistently framed as being "therapeutic." Conforming to the well-known cultural narrative that people with disabilities are tragic victims who need rescuing through heroic medical and therapeutic strategies is a wellestablished way for organizations to garner support, by framing themselves as heroes. However, some non-profits resist this narrative. This paper examines the organizational narrative of a disability-centered arts education organization that takes active steps to challenge the tragedy narrative by affirming the value of disabled artists and recasting stigma, discrimination, and misinformation about people with disabilities as the villain(s) in their organizational narrative. They portray society and art spaces as victims in that they miss out on the contributions to art that people with disabilities can produce. Still, the organization must also offer up to community stakeholders and potential donors reasons for its existence. This can be difficult in an ableist world in which disability is stigmatized or seen as a "spoiled" identity. Through narrative analysis of material posted on the organizational web-site of a community-based non-profit program that promotes inclusive performing arts education and performances, this paper explores the ways in which this organization navigates the competing demands of fund raising and disability advocacy by constructing organizational narratives that affirm people with disabilities while still articulating the value of the organization to the wider community.



Melinda Leigh Maconi is a doctoral candidate in the Sociology Department at the University of South Florida. Her areas of research include disability, health and illness, education, the arts, and identity. Her work is forthcoming in Research in Social Science & Disability and in International Perspectives on Inclusive Education. Her dissertation research focuses on art programs for people with disabilities, particularly those that reject the art as therapy label in favor of a focus on nurturing and promoting the artistic talent and contributions of disabled artists.

Member Announcements and Publications

Regatta Revisited: The Race for Equity in Virtual Sports

Kathleen A. Tarr -Stanford University, Doron Dorfman -Syracuse University College of Law, *Rutgers Law Record,* Vol. 46, 2018-2019

Abstract:



In today's internet driven world, virtual sports tournaments where competitors from across the globe use exercise machines connected via cyber technology are becoming increasingly popular. These competitions, in which athletes can participate from afar, have the potential to increase inclusion for athletes with disabilities. However, many virtual athletic competitions currently fall short of the mandate that organizers accommodate and reward disabled athletes in ways comparable to nondisabled athletes. Specifically, disabled athletes are far too often not equitably categorized into competitive classifications according to their impairments and disabilities. This discriminatory practice affects notions of fairness for disabled athletes. This note is the first to shed light on the regulatory and legal aspects of virtual sport tournaments and aims to recommend policy to ensure equity in those competitions for disabled athletes. Almost thirty years have passed since Congress enacted the Americans with Disabilities Act (ADA) which recognizes that "physical and mental disabilities in no way diminish a person's right to fully participate in all aspects of society." The Paralympic Movement is also very clear about the importance of comparable opportunities for disabled and nondisabled athletes as essential for the inclusion of the former and for reducing disability stigma. We argue that when competition and award categories are delineated across nondisabled sports, it is imperative that opportunities are mirrored for disabled athletes.

Please join us in congratulating Doron Dorfman, who will be joining the faculty at Syracuse University College of Law this Fall! He will be working with other departments across the university on socio-legal, empirical, research on disability law and health law.

Member Publications

"Don't look at it as a miracle cure: Contested notions of success and failure in family narratives of pediatric cochlear implantation."

Laura Mauldin - University of Conneticut Social Science and Medicine. Vol 228:117-25, 2019

Abstract:

Cochlear implants (Cls) are a routine treatment for children identified with a qualifying hearing loss. The Cl, however, must be accompanied by a long-term and intense auditory training regimen in order to possibly acquire spoken language with the device. This research investigates families' experiences when they opted for the



Attribution: Laura Mauldin, Portrait by Michael Ian NYC

Cl and undertook the task of auditory training, but the child failed to achieve what might be clinically considered "success" - the ability to function solely using spoken language. Using a science and technology studies informed approach that places the Cl within a complex sociotechnical system, this research shows the uncertain trajectory of the Cl, as well as the contingency of the very notions of success and failure. To do so, data from in-depth interviews with a diverse sample of parents (n = 11) were collected. Results show the shifting definitions of failure and success within families, as well as suggest areas for further exploration regarding clinical practice and pediatric Cls. First, professionals' messaging often conveyed to parents a belief in the infallibility of the Cl, this potentially caused "soft failure" to go undetected and unmitigated. Second, speech assessments used in clinical measurements of outcomes did not capture a holistic understanding of a child's identity and social integration, leaving out an important component for consideration of what a 'good outcome' is. Third, minority parents experience structural racism and clinical attitudes that may render "failure" more likely to be identified and expected in these children, an individualizing process that allows structural failures to go uncritiqued. It is time to begin planning the sessions for the 2020 SSSP Annual meeting in San Francisco. Typically, we have utilized our business meeting at SSSP to plan sessions for the following year's conference. However, last year we solicited session proposals prior to the meeting which allowed us to secure promises of exciting co-sponsorships prior to the meeting. Additionally, we are aware that planning the following years conference during business meetings does not afford the input of those who are not able to make it to the conference in the current year. Thus, we ask you to help us plan the disability sponsored sessions for the 2020 conference in advanced. This year we will plan 6-7 of the sessions prior to the meeting and use part of the business meeting to plan our other 3-4 sessions. We will not know the conference theme until July 1st and will send an email to all members at that time. If you have an idea for a session that you would like to see on the agenda that fits with the soon to be announced theme, please let us know. However, as in the past, we also will sponsor sessions that may be "loosely" tied to the theme – meaning that we encourage you to offer disability related topics whether the "fit" with the theme or not.

We ask that you email your ideas for session topics to Justine at jegner@uwlax.edu by July 24th 2019.

Please include the following information in your email:

1. The topic are you are proposing (it is best to keep this broad).

2. A SSSP division you think would be a good co-sponsor for your proposed topic (A list of divisions can be found at: https://www.sssp1. org/index.cfm/m/464/locationSectionId/0/The_Divisions)

3. An indication of whether you are willing to volunteer to organize the session, or if not, the name of someone who would be willing to organize the session (typically the sessions that make it to the program are the ones with a willing volunteer).

We will finalize our sessions for the 2020 meeting at the 2019 meeting in New York. We look forward to reading your suggestions and working together to plan the 2020 conference.

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