

## Editorial

### Editorial: Lessons Not Lost

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Recovery from the pandemic has highlighted many long existing inequities in access and quality of health care. Among familiar lines of wealth and class, much of the world is emerging from what we all hope to be the last days of a pandemic few will be sad to leave. Access to vaccinations and necessary care has spread unevenly across our global communities. At the same time, for many nations in recovery, in spite of considerable challenges, many citizens have found some benefits in unexpected types of access this time has afforded: the near universality of remote work, access to art and cultural events made widely available with accessibility measures and reasonable or free cost. There are some lessons many of us hope will not be lost in the after days.

Among these lessons has been greater questioning. As necessities of these days (that we still haven't agreed on a name for) have invited us to reimagine what work means, what education means, what art performance means, intensified calls for justice have insisted we also re-examine many of our other institutions. What should a just police force look like? This has been a central question that has only intensified during this period.

At the same time, there have been things neglected in our questions. In the United States, among calls for reform, little attention is brought to the lack of attention (and money) given to training those we entrust to serve. According to the Institute for Criminal Justice Training Reform, the average police officer in the United States gets less training than most plumbers, with most states allowing officers to serve before they have basic training.

Among the areas in which officers could receive better training is how to respond appropriately to the needs of people with disabilities. (Some organizations are making concerted efforts to make up for this gap by providing their own training to officers and communities, as the Arc does.) This type of training is especially important because of the neglected intersection of race and disability. What little data we have available suggests that the bulk of people killed in encounters with police in the United States are people with disabilities, perhaps as much as 70%; we do not know for certain. There has never been one single reliable database that keeps track. As President of the Board of the United States International Council on Disabilities Pat Morrissey's blog post in this issue's Notes from the Field section reminds us, data matters and can be a necessary part of the actions we take to ensure that the needs of all people with disabilities are met. And as Liz Weintraub, Senior Advocacy Specialist, AUCD Public Policy Team, regularly reminds us, "all means all."

With this in mind, we hope that among the lessons not lost in this extraordinary time will be the importance of greater data on the impact of police violence on the lives of people with disabilities, and most importantly, the right action to address it. Among these actions, we feel is the clear need for more wide-spread training (like the Arc provides) in identifying,

interacting with, and accommodating people with disabilities. This is of course not a uniquely North American concern. Our Global Perspectives editors and featured article remind us of the importance of cross-border conversations and the ways solidarity can amplify all our voices. These are among lessons we feel worth keeping as we reimagine our best possible futures together.



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## Editorial

### Disability and Multilingualism: A Global Perspective

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## Abstract

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*Keywords:* acid attacks, gender based violence, multilingualism, transnational

Another issue of our long envisioned and politically imperative issue of the Global Perspective Section of the journal is here. As we had imagined this section, we hope to create a space for multilingualism as a framework, political endeavor, accessibility commitment, and a cultural setting where languages appear more than an identity marker or private possession of a community. Creating this section, we hope to complicate what is disability as *injury*, and what it means to become, and remain disabled under exploitative social relations and oppressive historical continuities and discontinuities. To this end, we strive to create a space that challenges what we think as “normative” disability consciousness, “normative” disabling conditions, and “normative” disability expression mobilized by patriarchal, colonial, fascist, theocratic, and imperialistic legacies.

In the previous issue we included a story in Turkish and English by Nibel Genc, a political activist imprisoned in Turkey since 1994 defending the freedom and autonomy of Kurdish people. In this issue, we include a reflection piece by an acid attack survivor, Maryam Zamani.

Although acid attacks occur all over the world, this type of violence is most common in the developing world. According to Acid Survivors Trust International (ASTI), however, the U.K. has one of the highest rates of acid attacks per capita in the world (See <http://www.asti.org.uk/about-us.html>). In 2016, ASTI figures show there were over 601 acid attacks in the U.K., with 67% of the victims being male, but statistics from ASTI suggest that 80% of victims worldwide are women (Jack, 2017). Research shows that there is a significant difference between the intention of throwing acid on women versus men. It's believed that acid attacks on women are intended to disfigure them, isolate them, and make them “undesirable” to other men (Chowdhury, 2015; Cambodian Acid Survivors Charity, 2010; Mannan, Ghani, Sen, Clarke, & Butler, 2004; Welsh, 2009; Swanson, 2002), whereas acid attacks on men are intended to humiliate them (Evans, 2013). Acid survivors invariably face societal isolation, ostracism, social anxiety, avoidance, negative self-perception, and

decreased self-esteem, with little or no chance of ever finding employment. Added to the stigma of visible disfigurement, the acid survivor is most likely to experience both physical and psychological trauma (Mannan et al., 2004; Lansdown, 1997).

Maryam Zamani starred recently in a stage production titled *Vengeance in Crime* (between February 28 and March 17, 2021, at Mehregan auditorium) to bring attention to and raise awareness about the problem of acid attacks in Iran.

We offer a translation of her reflections. This was done under the oversight of our allies, Dr. Mehrak Kamali Sarvestani, a professor of Persian Literature at Ohio State University and Mr. Sepehr Manouchehri, a professional translator residing in Australia. The solidarity network that went into materializing this piece, just like the previous issue, is also noteworthy. We asked Maryam Zamani to write a reflection. Being a housewife, she is not used to typing in a Word document. We are not even sure if she has access to a computer. So, she used a pencil to write down her reflection in a piece of paper. We asked another disabled young woman, Omolbanin Shahmirzadi in a rural city in Iran, who makes a living by typing texts for clients, to put down Maryam's reflection in a Word document so we could upload it to the journal's website. Again, another network of solidarity was mobilized to render a survivor's voice audible to the world.

Reflective pieces like Maryam's, besides possessing truthfulness and clarity, have the power to challenge what we already know, namely, disablement via Gender-Based Violence (GBV). Having a disability analysis for a GBV should be at the heart of any intersectional analysis, especially when dealing with infliction of violence by a weapon such as a corrosive substance like acid. Maryam Zamani and her fellow survivors stay visible in the face of invisibility, ableism, misogyny, and destructive patriarchy.

To locate and echo Maryam's voice as an Iranian woman acid survivor, to find another disabled woman to type the piece, to have Mehrak and Sepehr edit the translation, and finally to materialize all of these endeavors collectively in this issue, is all a profound example of transnational solidarity. The journey of connecting the institutional dots, creating transdisciplinary conversations, building feminist and crip solidarity, and developing a multilingual analysis, is proving to be a pedagogical journey for us. Transnational solidarity transpires here in the following ways: first Maryam's recollection of violence and her gradual recuperation; her dramaturgy of the same in Persian; a plane act of penciling it down; its rendition in typography; formal translation into English by translators spreading across the continents; and its eventual appearance in English and Persian in this forum. This facilitation for Maryam's voice to be heard, via multiple layers of solidarity, is central to our Transnational Disability Studies project in this journal, because it provides "access" to the silenced voices at the margins of degenerative public and private spaces.

The feminist and multilingual engagement with an injured Iranian woman's voice, who has survived an acid attack with her three daughters, aims at defetishizing disablement by unmasking the naturalization of GBV in certain spaces and among certain people. We argue

that a transformative approach to transnational disability studies should be emancipatory in a sense that it not only explains (not just describes) the social relations and processes involved in injuring bodyminds but also possesses a revolutionary potential for ending those relations and stopping violence. By including Maryam's reflection in both Persian and English in this issue, we hope to bring alive a new rhetoric of translation.

Further, the dual linguistic presentation we hope may invoke at least three modes of activism:

1. Readers of Persian may see newer political meanings emerging beyond their cultural geography.
2. English readers, on the other hand, may become familiar with registers of debility that are not usually available to them. By debility, we mean structural excesses such as toxicity, environmental degradation, police brutality, domestic violence, and lack or no access to healthcare and education that systemically undermine people's sense of personhood, bodily integrity, and wellbeing.
3. And, when put together this way, the original and the story in translation do not perform as mere mirror images of each other. In some sense, they orchestrate what we call 'solidarity-speak'. During a solidarity speak adventure, languages in question do not compete with each other. Instead, they treat every translation endeavor as yet another feat of enrichment and moral openness.

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## Research Articles and Essays

### Videovoice Study Finds Transactional Benefits and Personal Impact of DPO Membership

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#### Abstract

This study investigates the experiences of Disabled Persons' Organization (DPO) members in rural North India. We utilize 'videovoice' methodology wherein participants create videos to explain the impact of their DPO membership, then expand further in interviews and group discussions. Thematic data analysis identified two meta-themes: transaction-type, immediate gains and personal or environmental impact.

*Keywords:* disabled people's organization, disability, videovoice

#### Background

Disabled persons' organizations (DPOs) and disabled persons' groups (DPGs) are representative organizations or groups of persons with disabilities or lived experience of disability, which aim to promote the rights of their members, improve their lives and create social support mechanisms (CBM, 2012; Enns, 2008; World Health Organization, 2011). The activities undertaken by DPOs and DPGs are not standardized but vary by context and constituency. Since 2007, the Nossal Institute for Global Health, working with the CHGN Uttarakhand Cluster, has supported disability-inclusive development in the state of Uttarakhand in North India. The main mechanism of the Uttarakhand Cluster has been supporting the formation of DPOs and DPGs. To date, eight DPOs have been established through this collaboration.

Despite DPOs being accepted as an important element in any approach to disability and development, there is little evidence of their effectiveness or impact on the lives of their members (Young, Reeve, & Grills, 2016). The process of DPO formation has been found to decrease barriers and increase access and well-being (N. J. Grills et al., 2020). Yet whether they in fact create new social or civil opportunities, influence individual or societal perceptions of people with disabilities and how any such impacts arise, remains poorly documented. Understanding how and when DPOs impact their members is therefore an important area that requires further research.

Addressing this gap using the novel participatory action research approach of

videovoice, we aim to generate data regarding DPO impact on members. Meanwhile, our methodology seeks to benefit participants, implementers and community members in Uttarakhand by creating platforms for self-expression and self-realization. Participatory action research in the form of digital storytelling can tap into the voices of DPO members in novel ways and further “advance an agenda for service provision and recovery that is built upon community, solidarity and social justice” (De Vecchi, Kenny, Dickson-Swift, & Kidd, 2016). While exploring the nature and extent of impact of DPO membership on their members and, by extension, their communities, we also aim to understand the value of this novel research methodology in disability studies.

### Methods

This study was undertaken by Nossal Institute for Global Health (University of Melbourne) in partnership with three organizations for people with disabilities in North India, with approval by the Human Research Ethics Sub-Committee of the University of Melbourne and the Ethics Committee of the Community Health Global Network – Uttarakhand Cluster. The study was conducted in locations where the partner organizations currently implement community-based inclusive development activities.

Additionally, this research uses the novel approach of videovoice, which is a health advocacy and promotion methodology wherein participants use participatory videography and interviewing techniques to identify issues of concern, communicate knowledge, and advocate for community health (Catalani et al., 2012). This methodology allows participants to intentionally construct the video and introduce a reflexive element in the capture of video (Holliday, 2000; Rich, Woods, Goodman, J Emans, & H DuRant, 1998). Videovoice reportedly aims to promote deeper understanding of lived experience, which can, in turn, serve to shape policy development (Gubrium, Hill, & Flicker, 2014), foster learning processes for participants (De Vecchi et al., 2016) and promote community awareness (Matthews & Sunderland, 2013).

To do so, videovoice builds on the photovoice methodology, which has been shown to be a robust method to explore factors that contribute to inclusion and well-being (Fernandes et al., 2018; N. Grills, Porter, Kumar, & Varghese, 2017; Reid & Alonso, 2018). Photovoice has also been used to investigate the experience of using mental health services (Tang, Tse, & Davidson, 2016) and to identify mental health concerns post-disaster (Ingram et al., 2018). It can create advocacy opportunities for people with disabilities and inform local programming for them (Han & Oliffe, 2016). Videovoice has not been implemented effectively in the field of disability, but its use in other fields has shown it to be an effective tool for gathering evidence and bringing about change.

In this case, the study was conducted in three locations across Uttarakhand state, following a modified version of the ten-point framework for photovoice (Hergenrather, Rhodes, A Cowan, Bardhoshi, & Pula, 2009). Purposive and convenience sampling was used to recruit 23 participants at the three sites: 15 people with disabilities (direct members of a



DPO) and eight carers of DPO members. To be included in the study, participants with disabilities were to be: (1) aged over eighteen years, (2) able to follow instructions and communicate verbally and, (3) members of a DPO for six months or more. Additionally, carers were to have been in their care-giving role for at least six months and unrelated by vocation to any participant with disability.

Additionally, male and female field staff were selected in each location by locally operating disability organizations and trained for research facilitation, including principles and objectives of research, ethics, video recording and storyboarding, interviewing and facilitation skills. A videovoice training manual was designed for the staff to ensure consistency across the sites.

With this structure in place, all participants gave written informed consent to participate in the study. Participants were instructed to take up to two minutes' worth of footage within a week depicting the impact on their lives of DPO membership. Field staff then followed an approved interview guide to investigate the motivations, ideas and sentiments behind participants' video clips. Participants explained what was in the clips, and generally what it meant or tried to convey. The interviews (conducted in Hindi) were audio-recorded, transcribed and translated into English.

Subsequently, transcripts from narrated videos, semi-structured interviews (SSI) and focus group discussions (FGD) formed the data for the analysis. Data were sorted under *à priori*-designated categories. The categories were determined according to the goals of DPOs and prior experience in disability research in the region. The list of *à priori* categories included skills, social, personal, information/awareness and material. Once data had been assigned to the categories, the data within each category was coded and thematically analyzed by the principal investigator. The themes were validated through discussion between investigators and with field staff.

## Results

**Table 1**

***Study Participants Disaggregated by Type, Sex, Age***

Description	Persons with disability		Carers	
	Female	Male	Female	Male
- Recruited	6	9	4	4
- Lost to follow-up / excluded	1	1	2	0
- Remaining	5	8	2	4
Of remaining, Age 18-30	3	2	2	1
Of remaining, Age 31-50	2	5	0	2
Of remaining, Age 51+	0	1	0	1

There were 19 eligible submissions (table 1). Four submissions were excluded by loss to follow-up (e.g., no answer in timeframe, out of age range). The data set was cleaned by

way of assessing correlation between the content in participants' videos and their responses to interview questions. Videos and SSI responses that did not address the research question (e.g., a video showed one participant's daily routine, and interview responses did not explain change in relation to DPO membership) were excluded from analysis. One was excluded from site C and D respectively, but these two participants still contributed to the FGD (Table 2). All videos and transcripts from site E were analyzed. Validity of response was not associated with sex or disability. The findings from the analyzed data are presented firstly as themes and secondly in a hierarchy of categorical significance by demographic.

**Table 2*****Numbers of Study Participants Disaggregated by Site (of Data Analyzed)***

Descriptor	Site C	Site D	Site E	Mean / Total
Geography	Plains	Hills (not remote)	Plains	n/a
No. pax	7	6	6	Total: 19
Male:Female	5:2	3:3	4:2	M=12; F=7
Disability:Carer	6:1	3:3	4:2	D=13; C=6
Focus Group Disc.	8	7	5	20
Age range	20-60	19-60	24-35	Mean: 37

Thematically, the impact of participation in a DPO/DPG was typically represented in two ways. The members and their families/carers spoke of rather immediate transaction-type gains (i.e., I join and I get...), and/or of the spins-offs that affected the person and/or their environment.

**Transactional gains**

Transactional gains are classified by the kind of rewards that a member and/or their family will 'get' from joining a DPO. They are expressed in many of the responses, some as the main benefit of joining the DPO, some as secondary spin-off-type gains. Some participants noted that these benefits made them happy or had a positive impact on their personal state.

**Information / awareness**

Joining a DPO/DPG afforded most participants with information and knowledge gains that made them happy, grateful or relieved. Increases in knowledge and/or access to information related to government disability pensions/schemes, rights of persons with disabilities and/or options for care of persons with disability (e.g., therapy services or techniques).

While some participants spoke of simple knowledge gains, such as becoming aware of the local area and services, others like participants C03 and D01 expressed how these gains had affected them personally:

*“... earlier we didn’t know anyone and also [didn’t know] about anything. But now we know and have information about the government departments and all.” – FGD-E*

*“We have understood our rights. We are very happy. We feel very good by joining in the group.” – C03*

*“Through the DPG I gained knowledge of where the police station, block office, bank, and [other services] were, and I gained knowledge about these places ... My participation through the DPG helped me to go out of my home.” – D01*

The information/awareness was transmitted through participation at DPO/DPG meetings and/or workshops, receiving information in a formal sense or through fellow members, as explained above and by the following individuals:

*“When we go to meetings, we learn so many good suggestions.” – C09*

*“After becoming a member of the DPO what I have liked most is we have got an opportunity to come forward and we can share our personal experience with DPO [members] and the benefit we have found is, when we share our experience with others we get various information to grow.” – C06*

This type of benefit of participation was described with gratitude and a sense of relief: material relief through access to government services (as per D06, cited below); personal relief through access to support services (therapy or otherwise) (D07); and, personal relief afforded to members and their carers/family (C09):

*“Since we joined the DPO we got to know a lot of things and the DPO also helped us a lot.” – D06*

*“I didn’t have knowledge but after joining the group I gained knowledge and I have got lots of benefits.” – D07*

*“We get good quality and lessons. So, I like this group.” – C09*

Additionally, a small proportion of participants expressed their interest in others with disability becoming part of a DPG in order for them too to benefit in similar ways. Two young participants, C06 and C01, exemplify this in their comments:

*“I want everyone to know their rights. And after becoming the member of DPO group, I have got this information.” – C06*

*“I want that the kind of change that has happened in my life to happen in the lives of my other disabled brothers and sisters.” – C01*

### Material benefits

Another very tangible ‘benefit’ frequently referred to was material gain. Participants reported what they had acquired from joining the DPO/DPG: goods such as chickens (to undertake livelihood activities), toilets, assistive devices and access to government pensions. With respect to the latter, participants noted that they had gained access to a pension – some calling it ‘financial help’ – thanks to the information or facilitation the DPO had given them:

*“After joining the DPO group, we have got this profit, that ... my pension is being made. We have been able to see many good things. Free of cost, we travel to different meetings. In a great way, the government is supporting us.” – C09*

*“We benefited after being together as a group; we were able to make our pensions/ certificates whereas when we were alone if we went we would not be able to get the work done but now it has changed.” – E02*

The latter quote shows the sense of collective action that facilitated access to the pension, which in turn allowed persons with disabilities to begin working according to their rights.

### Skills

The acquisition of skills was both direct and indirect – direct, where participants had had the opportunity to participate in livelihood skills training facilitated by the DPO (as per C03, below), and indirect, through access to education opportunities and through increased confidence to learn new skills (as per C01):

*“After joining the group, we have gone through various trainings like candle making, mushroom composting and many more.” – C03*

*“Whatever change that has happened in my life is through the DPG. I have now completed my studies and am preparing for a job.” – C01*

Acquiring these skills helped members achieve what they would otherwise not have been able to, e.g., expand their livelihood activities, further their education, or gain independence.

### Personal and social impact

A strong focus of respondents’ explanations of the impact of DPO/DPG participation related to the changes in their personal and social situation – in their social relations, their self-esteem and attitude towards disability, and/or in their outlook on life.

#### Personal

Three kinds of personal change were evident in the participants’ responses: awareness, confidence and motivation. Through exposure to information about the rights of people with disabilities, and from interacting with other people with disabilities, DPO members gained a reference point for their own experience of disability:

*“We came to know each other. Even this is what we came to know: that there*

*are many who are like us.” – E04*

*“I used to think that I was the only person with disability alive... [At the DPO], I saw there were many people who were more disabled than me who have difficulty in walking. When I saw them, my spirit was uplifted.” – E02*

This awareness altered the participants’ mindset towards disability, and reduced their fear of disability, their fear of being counted or of interacting with others outside the home. The following citations demonstrate how members of Uttarakhand DPOs experienced a paradigm shift in regard to their social relations and civil participation:

*“People with disabilities are still in darkness. They think so much but are unable to do anything. They feel scared to do anything and keep thinking about what society will say about them. ... We have to go from darkness towards the light. We need to keep our voice and opinion in front of society so that they also know that we are capable of doing something. We accept that we are disabled, but we are disabled only physically, but not disabled in our minds.” – E06*

*“I started meeting people. I was not able to talk with people the way I am doing right now. If a guest came to our house, I was always inside my room. All these people here are from my village, but I never knew them. They also didn’t know me.” – FGD-E*

DPO members had come to recognize the ‘darkness’ and ignorance about disability that had clouded their minds and had limited their imagined possibilities. Involvement in a DPO gave them an awareness of their value and rights, which provided a platform for new life experiences.

By extension, participants also improved their self-image and confidence, in some cases finding an added motivation to ‘do something’:

*“I have been busy after joining the group and taking care of my livelihood/earnings.” – E02*

*“I stay happy now, and the desire to live has grown in me. Now I do tailoring, I study and also help in the chores of the house.” – E01*

*“I thought I should start a livelihood, and for that I took a loan from the DPG, and in time returned it faithfully to them, and I did my own livelihood. Now I purchase things on my own, and by selling the things I am able to make my own earnings.” – E02*

By now operating with greater confidence, skill levels and self-respect, DPO members could also feel more independent and exert that independence confidently, as C03 captures in her statement:

*“... we always want to remain in the group and enlarge our work and make ourselves independent so that we don't depend on anyone. [We want] to make our own identity. We want to live with self-respect. We want to have our specific identity. We should be able to do our own work. We should work with our own hands. We don't want to give our work to anyone else. Through the group only, we can do all these things. Alone we can do anything.” – C03*

## Social

In addition to the impact of membership on a person's well-being and self-perception, it also led to growth in social interaction, through the enlarging of their social networks. The following quotes demonstrate the new openings in members' social lives:

*“[The title for my video is] ‘Knowing and being familiar’.” – E04*

*“The biggest change [since joining the DPO] is that we started knowing each other.” – FGD-E*

*“Since joining the DPG I have benefitted in many ways. Earlier, we were not in this position, because we had never come out of the family and stayed in our family, and we never used to talk with people around us. We used to feel shy in front of people. But when we joined the DPG we gained confidence and we felt so good by meeting different people. And there have been other changes as well.” – C03*

Thus, the benefits of membership had been getting to know others, ‘getting out of the family’, beginning to ‘talk to people around us’. One carer (A04) reflected that some members had ‘merged into society well’.

Furthermore, among some (like C01, C04 and C06) was a sense of collective identity and potential, the creation of support networks and the DPO becoming like family to them:

*“We want our DPG to develop further together, and through unity we can grow together and we can do anything. Having unity within us is very necessary for us.” – C06*

*“We all disabled brothers and sisters come together, and we try to understand each other's feelings. We try to understand what their needs are and what their problems are. We try to solve their problems.” – C04*

*“I thank the DPG, which is my family... Earlier I used to stay alone, as I used to feel that people would make fun of me if I went out of the house.” – C01*

One participant (E02) believed that their collective action had shifted societal perception, explaining they had held a rally to showcase “[people with disabilities] can do something good” and change attitudes towards them. Another (C05) reported that his community had stopped discriminating against him:

*“Earlier people use to look down on me. They used to tell others not to come*

*close to me. Now the people do not do that or say such things. Now I am able to stand on my feet and work. If I can stand up and work, so can you.” – C05*

### **Hierarchy of categorical significance**

The data were assessed in terms of the frequency a certain response type was given, and by demographic. The quantitative analysis highlighted the importance to respondents of personal and social impact – 50 percent of dialogue focused on these topics. Information/awareness and material benefits comprised 40 percent of dialogue, while skills and other accounted for only 10 percent of dialogue. In terms of demographic distinctions, participants at sites C and E showed gratitude for personal benefits, while those at site D noted the helpfulness of information/awareness opportunities. Participants with disability cited the personal gains ahead of carers who noted the information/awareness-related benefits. Between participants with disability versus carers were moderately different orders of response, although carers and persons with disability both recognized the social, material and ‘other’ benefits to similar extents. Males tended to focus more on material gains while females were primarily concerned about the personal benefits. This was consistent in responses across age ranges.

### **Discussion**

Through engaging DPO members in participatory action research using voice via smartphone technology, this study generated interview-based data that demonstrated positive benefits of DPO/DPG membership. Participants articulated that the impact had been both personal and social, often by virtue of the information/awareness, material and skills-based gains. No inherently negative effect or impact was reported.

First, if the goal of DPOs is to promote the participation, well-being and rights of persons with disabilities (World Health Organization, 2010), then this study confirmed increases in participation in domestic and social activity, some degree of improved well-being in terms of physical functioning and livelihood capacity, and notable improvements in member knowledge of rights. Participant expectations and motivations for joining the DPO were not assessed so we were unable to determine the degree of congruence between expectations and experience. There was some indication from the data, however, that members joined ‘to get something’ (material, informational, opportunity-related), which the data also indicated was attained from participation.

Meanwhile, this study yielded numerous accounts of participants finding courage to participate more actively in domestic life, livelihood activities and the community, having become more aware of their own personal value and ‘validity’ in the world or having gained new skills. As in the cases of E01 and D01, “This inferiority complex I had is finished,” and, “Wherever I have to go, I go freely. Before, I was very scared to go to the market but now with the help of the DPG group I am more confident.” These findings concur with those of Young et al. (2016), who noted increases in confidence, and of Leung et al. (2019), to whom DPO members reported “increased social connectedness, personal development, livelihood,

improved sense of community, and participation within the family.” Many members in this study spoke of the DPO as being a place they belonged, felt comfortable and were accepted, a place where they could bring questions and find answers.

Furthermore, the socialization that Montgomery et al. (in press) and Young et al. (2016) describe as being a key outcome of DPO participation has also been confirmed by these data. The DPO has enhanced “the breadth and diversity of social networks” by expanding members’ social circles, increasing their desire to socialize, and creating the impression that others in the DPO/DPG are “like family.” Concurring with findings of Montgomery et al. (in press), our study found that increased social connections are associated with greater confidence/self-esteem, greater access to services, and increased opportunities for friendship/advocacy.

Whereas Young et al. (2016) noted the role of local village leadership in establishing and sustaining DPOs, this data did not reveal that the presence or influence of village leaders was important for the DPO outcomes. As the research question focused the attention of benefit on the member and not on wider societal shifts related to the organization/group’s establishment/existence, participants’ responses focused on changes at the individual or family nucleus more than at the societal level. However, some participants indicated that opportunities for collective action, lobbying and awareness raising had been created and utilized. The findings are thus consistent with the few prior studies into this question (N. J. Grills et al., 2020; M. Leung, A. Devine, L. Singh, T.-W. Yip, & N. Grills, 2019; Montgomery et al., (in press); Young et al., 2016), but further exploration of the impact of the DPO on collective action and/or the social environment would help define the broader-reaching impacts of these structures.

Evidently, some variation in the participant experience of the DPOs was anticipated. As compared to those with disability, carers ordered the importance of outcomes differently, reflecting their different experience of disability. However, both carers and persons with disability recognized the social, material and ‘other’ benefits to similar extents. Comparing responses between the sexes, women seemingly valued personal and social benefits more highly while men placed more emphasis on material and information/awareness-related gains. This reflects the gender-specific roles in rural India whereby the male is typically the breadwinner, and the female is more involved in family duties and individual caregiving. Differences in age, however, did not tend to influence respondents’ values remarkably.

Finally, the study unveiled pathways from immediate transactional-type gains (information, awareness, skills, material goods) to personal and social impact, without explicitly exploring the mechanisms or conditions for the impacts to have taken place. Further to the pathways or explanations noted, the data suggests that supportive family, social and physical conditions/environments must be established in order to realize the benefits of membership. For example, family support was raised as important in facilitating achievements and changes for participant E01. For DPOs to respond to evidence and ensure that conditions are optimal for impact, there may be some benefit in exploring theory-of-



change models in subsequent studies.

As concerns the methodology, the participatory action research approach to data collection successfully engaged persons with disabilities in generating findings on DPO impact through their own voice rather than that of spokespersons or representatives. This allows DPOs to enhance their activities, promote the importance of DPOs, raise awareness about disability and advocate about the roles and rights of people with disabilities – a stated aim of this approach. However effective this method was in achieving the aims of the project, it was not clear that videovoice was significantly superior to the photovoice approach (antecedent to videovoice) used by the authors in the same geographical area (N. Grills et al., 2017). As literature suggests, both approaches generate rich data, contribute to advocacy opportunities and informed local programming for people with disabilities (Han & Oliffe, 2016). In practice, however, videovoice was considerably more difficult than photovoice, given the participants' unfamiliarity with story building or film generation and their camera shyness. Videovoice also required a higher level of competence in effective use of smart phones, and specifically the confident use of the video application.

Furthermore, a lack of confidence among participants to complete the task required field staff to spend longer than expected explaining and supporting participants to capture a story of personal relevance and impact. This created a risk of bias whereby fieldworkers may have suggested ideas in explaining the process. However, the field staff did not accompany the participants whilst filming, and the semi-structured interviews allowed participants to voice relevant responses without field worker involvement.

In essence, photovoice could have been simpler and may have produced similar findings, however feedback from the field staff concerning the methodology alluded to the positive nature of the exercise insofar as it created learning opportunities for participants around technology that may offer a new mode of self-expression and communication for them (e.g., potentially leading to use of social media platforms where available). Thus, in deciding to use videovoice over photovoice or other qualitative methods, one must consider the research question being asked, the familiarity of participants with adopting technology, ethical considerations, and the importance of empowerment of the research participants. As a research methodology, videovoice would be useful for capturing stories that have more content than a before-and-after story line, and for exploring topics that require a particularly visual response.

### **Conclusion**

This study aimed to provide DPO members of rural North India with a novel, participatory means of assessing the DPO's impact on their lives. It vividly captured the experience of participating in a DPO, and revealed the transformative impact of DPO membership on personal and social circumstances as a result of transactional-type gains. In particular, increased understanding and awareness of disability and disability rights, together with greater socialization, had given members confidence and motivation for greater social

and civil participation. Additionally, the participatory action research methodology helped empower participants to generate community recognition of their situation, advocate for their rights and promote societal change. Videovoice, despite the technical challenges, proved an effective methodology in the field of disability for describing impact and advocating for change.

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### Conflicts of Interest

None declared.

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**Research Articles and Essays****“Nothing About Us Without Us”:  
Involving People with Dementia in Qualitative Research**

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**Abstract**

People with dementia are increasingly asserting their rights as people with disabilities. Yet instead of inviting them into studies as participants, researchers often use surrogates—family members or healthcare professionals. I address this problem by bringing together qualitative methodologies that involve people with dementia directly in research.

*Keywords:* dementia, disability, research participation

A new disability rights movement of people living with dementia has emerged. Members of this movement are tackling social dis-ablement and structural discrimination against those with dementia (Crowther, 2016), rather than viewing it only as a medical diagnosis (Shakespeare, Zeilig, & Mittler, 2017). This shift is similar to the process by which chronic illnesses and mental health conditions, once viewed only through the medical model, are now considered disabilities. There are many similarities in the ways in which younger adults with developmental disabilities and older adults with dementia are devalued and infantilized. They are often considered burdens on their caregivers and frequently left out of decisions about their own lives. Yet these two groups of people with cognitive impairments exhibit agency by resisting the exercises of power over them. For example, Oldfield & Hansen (2020) show how “Susan,” who had a cognitive impairment her entire life, resisted being given orders by loudly exclaiming “I won’t!” “Helen,” who aged into cognitive impairment, resisted ableist devaluation by reframing her life changes positively. She explained, “I used to have a photographic memory, but it’s gone. But I have lots to be thankful for. I’m in good health” (Hansen, 134). Helen spoke positively of her changing body, saying “There’s a reason for my body changing as I get older. It wants my attention. I listen and take care of it ... I veer to the left, so now I use a cane to keep walking straight” (Hansen, 134).

Dementia activists Steele, Swaffer, Carr, Phillipson, and Fleming (2020) state that “people living with dementia are full humans, equal to everyone else,” and thus have human rights. Indeed, people with dementia are covered by the definition of the UN Convention on the Rights of Persons with Disabilities (CRDP): “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (Crowther, 2016, p. 2).

“Nothing about us without us” has long been a slogan among disability rights activists to proclaim that all research, policymaking, and public activities concerning disability, should include participants with impairments (Williams, 2011), who should also be enabled to access public spaces and be represented in popular culture. Yet qualitative research on dementia often excludes people with lived experience (Novek & Wilkinson, 2017; Steele, et al., 2020). Instead, researchers still ask formal caregivers, health professionals, or family members to speak on behalf of people with dementia, even when they are verbally articulate.

Problematically, others’ accounts may ignore the perspectives of people living with the condition or be filtered through dominant discourses about dementia. These discourses frame it is a tragedy to be feared (Van Gorp & Vercruyse, 2012) and thereby something to be detected early so that it can be mitigated. Additionally, representations of people with dementia focus on deficits (Zeilig, 2015), not assets, such as “Disability is creativity at a moment’s notice” (N. Hansen, personal communication, March 20, 2021). Although family members and care workers may be able to observe the actions of people with dementia and reflect on them, they do not directly experience the phenomenon. Instead, they may filter it through the lens of negative representations of dementia. For example, media stories often describe people with dementia as patients “suffering” from it. They tend to take the viewpoint of adult children who feel that they have lost the parents they knew and that those parents have already died.

Media stories from the viewpoint of people living well with dementia are rare. However, Reimagining Dementia: A Creative Coalition for Justice, an international group of dementia activists and allies, challenges negative representations of dementia through play and the arts ([changingaging.org/dementia/reimagining-dementia-a-creative-coalition-for-justice-join-us/](http://changingaging.org/dementia/reimagining-dementia-a-creative-coalition-for-justice-join-us/)). Because dementia is often seen through the eyes of nondisabled people, to accurately understand dementia it is crucial to directly involve people with dementia in research on the topic (Nygård, 2006).

This essay is informed by scholarly literature and nonacademic reports and websites, as well as research in which I explored how three types of time intersect in a North American nursing home. (These institutions are also called “long-term care facilities,” “care homes,” and “residential aged care.”) (Oldfield, in progress). The first type is institutional time, the dominant force structuring daily life for both staff and residents. The second type is residents’ time, which is how residents prefer to structure their daily lives. The third type is dementia time, the unquantifiable, fluctuating timescape of people with dementia (Yoshizaki-Gibbons, 2020), who comprise the majority of nursing-home residents. The research is part of an ongoing informal critical ethnography that centers on Helen, one of my family members, and her fellow residents. Critical ethnography, a methodology that incorporates observation, interviews, and reflection, exposes power differentials to promote social change (Ross, Rogers, & Duff, 2016). My ethnography is guided by critical disability studies, which looks at power relations from the perspective of people with impairments. The discipline counters the mainstream view of disability as tragedy by pointing out its advantages. For example, memory loss in dementia can be a benefit. As Helen explained, “I’m getting more and more

content ... And I'm not looking a way ahead, wondering about things; I'm living *now* and *today* ... I'm not restless ... I'm actually quite peaceful, which is surprising" (Oldfield & Hansen, 2020, p. 134).

In this essay, I bring together four challenges with qualitative research in a nursing home involving residents with dementia: (a) gaining access to the research setting, (b) informed consent from participants with dementia, (c) working with participants who have dementia, and (d) mitigating emotional distress among researchers. For each challenge, I discuss how it may be addressed. At the end of the essay, I focus on one methodology, ethnography, which is particularly appropriate for exploring dementia with nursing home residents.

### **Gaining Access to the Research Setting**

As a member of Helen's family, my access to the institution is unquestioned, although I must sign in and out at the security desk as every other visitor and staff member does. For researchers who do not have a family member living in a nursing home, gaining access can be more difficult. They will need to first build trusting relationships with administrators to gain permission to access not only the institution's spaces, but to recruit participants. Where permission is attainable, it is more likely to come from institutions who want to showcase their culture change, rather than from more traditional institutions. In the landscape of North American nursing homes, where many facilities are owned by for-profit corporations, competition for business may prevent corporate owners from risking scandals and damaged reputations by allowing researchers in.

### **Informed Consent from Participants with Dementia**

One reason for excluding people with dementia from research is the assumption that they cannot give informed consent. Moore and Hollett (2003) challenge conventional measures for determining competence to consent. They argue that research participants are not required to be competent in making decisions about all areas of life but only a specific decision in a specific context. The CRDP recommends that shared decision-making replace substitute decision-making for people with disabilities. Nonetheless, even in some countries that have ratified the treaty (e.g., Canada), substitute decision-making is still the legal default (Walker, 2013). Seniors are advised to designate proxy decision-makers as part of advanced care planning, and these proxies hold sway in decisions about the lives of nursing-home residents. Therefore, research ethics boards may require proxies to give informed consent for participation in research. However, researchers can model techniques for sharing decision-making to ensure that participants with dementia take part in the consent process. These include using pictures to explain abstract concepts and involving trusted people (e.g., peers) who have listened to residents' wishes (Williams & Porter, 2015). Ensuring that their proxies are willing to share decision-making can be a criterion for selecting participants.

Nygård (2006) recommends that researchers build relationships with participants who have dementia well before requesting informed consent. During the research, researchers should remind participants who the researchers are, the purpose of the research, and that they are temporary visitors. Steele et al. (2020) note that the importance of obtaining ongoing consent during data co-construction by reminding participants of their freedom to participate, take a break, ask for support, or withdraw from the study. Moore and Hollett (2003) add that ensuring that participants understand the researcher's role is essential to continuing consent. Looking for verbal and nonverbal signs of anxiety can help researchers assess participants' willingness to continue (Pesonen et al., 2011).

### **Working with Participants who have Dementia**

Involving people with dementia in research may require adapting research methods to take into account the needs of participants with cognitive impairments. The Scottish Dementia Working Group (2014), an advocacy organization of people with dementia, advises that researchers should:

- be empathetic, unpatronizing, and tolerant;
- communicate in inoffensive language that participants will understand;
- find out the best time for participants to meet, how they each keep track of time and want to be reminded of meetings;
- ask participants if they would like to have someone with them;
- ask about participants' emotional and physical safety needs at each meeting;
- offer access to counseling or emotional support;
- recap previous conversations at each meeting;
- give participants time to reflect and respond to questions;
- offer regular breaks;
- be cautious about asking participants to recall unhappy times, as they may trigger pain; and
- not stay longer than agreed, unless invited.

Dementia researchers suggest ways to adapt interview techniques for participants with dementia. These include scheduling interviews for when participants are mostly likely to experience the study phenomenon (Moore & Hollett, 2003). An unstructured interview format may be most adaptable (Nygård, 2006), in addition to fostering co-construction of knowledge. It also allows participants to direct the conversation to issues that matter to them (Moore & Hollett, 2003). Photo-elicitation, in which researchers ask participants to bring photographs to interviews that have meaning for them and then use the photographs to elicit stories, can be used to make interviews more concrete. Photographs and other objects in residents' rooms can also elicit stories. In asking about participants' daily lives, researchers should formulate questions that do not require recalling events or feelings (Nygård, 2006) and focus instead on participants' strengths (Moore & Hollett, 2003). Photovoice (Dassah, Aldersey, & Norman, 2017), which entails giving cameras to participants and asking them to



photograph aspects of their lives that are important to them, can provide material for participants to discuss during interviews.

Williams (2011), in her book about conversations with people who have intellectual disabilities, asserts the need to avoid replicating day-to-day oppression. She advises presuming competence, ensuring conversation partners that you believe what they say, waiting for them to respond, following up on responses, and using friendly body language (smiling, sustaining eye contact, and showing interest through facial expressions). Pesonen et al. (2011) also advise researchers to use communication strategies “such as active listening, using concrete words, repeating questions differently if necessary, [and] tolerating silence” (p. 656).

‘Go-along’ interviews (Carpiano, 2009) facilitate the co-construction of data between interviewer and participant. Informally interviewing someone while accompanying them for discrete periods of time in their daily lives enables more concrete questions, prompted by things that both researcher and participant observe in the same moment (Nygård, 2006). Participants can also demonstrate what they mean (Nygård, 2006), adding to the richness of data. Photography can be used to document the locations visited and what was observed. The photographs can then be used to remind participants about the shared experiences in later interviews, where they can be explored.

Although interviews can be adapted for people with dementia, they usually rely on verbal communication. People with dementia or other cognitive impairments (e.g., stroke, neurodiversity, intellectual, or acquired brain injury) or Deaf people may communicate without using words. Interviewing participants who communicate differently requires a nonconventional approach. Teachman, Mistry, and Gibson (2014) developed such an approach to interviewing youth who communicate nonverbally using eye gaze, gestures, facial expressions, and technology. Their methods include observation, photo-elicitation, face-to-face and electronic interviews. The researchers are assisted by family members in becoming familiar with participants’ communication modes. Bourbonnais and Ducharme (2010) used a triad methodology to explore communication without words among people with dementia in a nursing home. Each triad comprised a resident with dementia, a family member, and a healthcare professional or a paid caregiver who knew the resident well.

Analyzing and interpreting data co-constructed with someone who has dementia may require novel approaches. It may help to create an advisory committee of people with dementia from outside the study setting, perhaps recruiting committee members through advocacy organizations of people with dementia, such as national chapters of Dementia Alliance International. Committee members can participate in the development of research questions, data analysis and interpretation. Data would, of course need to be de-identified (e.g., names and any other identifying details removed from transcripts and observations) before sharing it with advisory committee members. In addition, researchers can share the findings with participants, in ways adapted to their abilities, to check whether the findings resonate with their experiences. Visual methods (e.g., putting themes or concepts on cards,

illustrating them with pictures, and asking participants to comment on the themes' or concepts' resonance with their lived experience) may work for member checking and can also involve participants in data analysis. Similarly, researchers can, in collaboration with participants, draw conceptual diagrams to interpret data. Advisory committee members can help translate knowledge from the study findings and share it with nonacademic audiences.

### **Ethical Issues in Working with Participants who have Dementia**

Because relationships are so important in dementia, researchers should plan if and how they will withdraw from the setting (Moore & Hollett, 2003). Heggstad et al. (2012) point out that participants with dementia may perceive researchers as having power over them. Therefore, it is important to avoid increasing their vulnerability. As nursing-home residents, they are already objects of institutional power (Oldfield, 2019). Heggstad et al. advise researchers to keep a log about what ethical challenges they encounter and how they resolve them, possibly in consultation with health professionals and family members who know participants with dementia well. These methodical memos become data on which researchers can reflect during analysis and interpretation. The memos can also comprise an audit trail, in case researchers need to defend their decisions to research ethics boards or others.

People with dementia may not have been told their diagnosis, because the word confers stigma and invites stereotypes (Pesonen et al., 2011). Therefore, the authors advise against using this label (as it might be regarded through a critical-disability-studies lens) unless participants describe themselves this way. Instead, the authors used the term “memory problems” to prevent participant distress. When I interviewed clients of employment agencies serving people with disabilities (Gewurtz et al., 2019), I used whatever identity the participants adopted at the beginning of the interview when they described themselves and their job search. Similarly, when I talk to Helen, I avoid the term ‘dementia,’ an identity she has not adopted. Instead, I refer to memory loss because she brought the issue up herself. As a group member with dementia emphasized during a meeting of Reimagining Dementia in 2020, “If you’ve met a person with dementia, you’ve met just one person with dementia. We are all different.”

In alignment with the disability-rights-movement slogan “Nothing about us without us,” Heggstad et al. (2012) argue that “Not including vulnerable people in research may even increase their vulnerability. More knowledge [from the perspective of people with dementia] may also reduce the stigma associated with the disease and lead to more openness around it. Excluding persons with dementia from important research may be unethical and also a threat to their dignity” (Heggstad et al., 2012, p. 37).

### **Mitigating Researchers' Emotional Distress**

Doing research in nursing homes with people who have dementia may put researchers at risk of emotional distress. The Scottish Dementia Working Group (2014) recommends that researchers “become aware of their own ‘safe zones’ and know where to go/not go” (p. 683).

Individual researchers will, of course, interpret emotional safety differently according to their personal history and circumstances. Ethical and methodological uncertainties, along with ending relationships with participants can evoke distress (Pesonen et al., 2011). These authors recommend that researchers keep reflexive diaries and share their emotions with supervisors.

Next, I offer suggestions for emotional safeguards from my own experience. In a seminar I attended, a nursing-home researcher talked about feeling upset when she observed low-quality care (J. Choinere, Centre for Critical Qualitative Health Research seminar, January 16, 2019). I have certainly felt distress when witnessing how institutional power impinges on quality of life for Helen and her fellow residents; for example, when staff members demean residents or give them orders (Oldfield & Hansen, 2020). Over the years of my ethnography, I have developed relationships with some residents, and some have died. Their deaths have not been acknowledged by the nursing home. To let go of the anger I feel while observing these situations, I find it helpful to audio-record my feelings and reflect on them as soon as possible. As a family member, I am very careful not to criticize the home or its staff members. I strive to maintain pleasant relationships with them, not only to avoid defensive reactions but to protect Helen.

Discussing my observations with a family member of one of Helen's fellow residents who has become a friend and fellow advocate somewhat alleviates my distress. She is very familiar with the nursing home, coming daily to help her family member eat dinner. Both of us attend meetings of the home's Family Council, where we receive additional peer support. This informal support is one of the strategies recommended by Dickson-Swift, James, Kippen, and Liamputtong (2008). They also advise researchers investigating emotionally sensitive topics to look beyond peer support by taking the following actions: leaving time between data-collection episodes to process emotions, developing guidelines for ending research relationships and strategies for dealing with participant death, and having someone else transcribe interviews to avoid reliving traumatic experiences. If an advisory committee is involved in the research, they should be given access to the above strategies for mitigating emotional distress. They can also provide support to the researchers to mitigate emotional distress. By discussing their emotional reactions to the data and findings, advisory committee members and researchers can co-create reflective data.

I now look at how qualitative research, and one qualitative methodology in particular, ethnography, suits research involving nursing-home residents with dementia.

## Ethnography as a Methodology for Exploring Dementia in Nursing Homes

Although quantitative research approaches are well suited to investigating countable institutional phenomena, qualitative approaches, such as ethnography, are better suited to investigating residents' perspectives because they are not easily quantified. Ethnography also involves researchers building relationships with participants over time. This time can increase researchers' understanding of the study context and enable them to get to know participants as individuals (Heggstad et al., 2012).

Ethnography enables researchers to draw on multiple data sources; for example, observation (participant and non-), document analysis, formal interviews, informal conversations, field notes, and memos. These multiple sources create a richer dataset than single methods may. Except for interviews, these methods do not require participants to recall past events or feelings. By focusing on the here and now, the other methods may be work better for people with dementia.

Researchers can compare data from different sources to identify similarities and differences and use one method to flesh out findings from another (Nygård, 2006). For example, during interviews, researchers can follow up on themes from their analysis of observational data, or vice versa (Heggstad, Kari, Nortvedt, & Slettebø, 2013). Ethnography also puts participants' situations in context, which can be investigated using other methods, such as document analysis. Because one way to adapt research for participants with dementia is to schedule multiple, short interviews, working with the same participants over time may enrich the data and facilitate data interpretation (Nygård, 2006). Ethnography allows for such longitudinal research, involving multiple interactions with participants at different times and perhaps in different contexts. Multiple interactions allow time to build trusting relationships between participants and researchers (Pesonen et al., 2011). Finally, triangulating data from multiple sources increases rigor.

### Conclusion

Although all qualitative research about disability should include participants with lived experience, researchers rarely invite people with dementia to participate. Instead, they seek input from proxies, family members, care providers, and healthcare professionals. These indirect accounts may be filtered through dominant discourses about dementia and inaccurately reflect the perspectives of people living with the condition. In this essay, I offered suggestions for involving people with dementia directly as research participants.

Critical disability studies, through its insistence on including people with disabilities in disability research, has much to contribute to qualitative research that includes people with dementia, and to social change. The approaches, methods, and ethical issues covered in this article can contribute to research that includes people with other cognitive impairments (e.g., from stroke, neurodiversity, intellectual disability, or acquired brain injury).


Researching dementia through the lens of critical disability studies will help move dementia out of the medical model of disability into the social and human-rights models. This will shift thinking to the view that people with dementia are dis-abled by society and are protected against disability discrimination under the UN Convention on the Rights of Persons with Disabilities and the human rights laws of countries that ratified this treaty. Returning to the disability-rights slogan, “Nothing about us without us,” research that more accurately reflects the views and experiences of people with dementia will provide a better foundation for planning dementia services and supports, policy making, and dementia-friendly social and physical environments. With time, research that includes people with dementia will help change how people with dementia are viewed by their families and friends, healthcare providers, and society as a whole—not as victims of fearful tragedy but as people with impairments who have meaningful lives.

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## Notes from the Field

### Poems by Glenn Merrilees

Glenn Merrilees

**Abstract:** Poetry exploring the experience of mental illness by Glenn Merrilees.

I'm 56 years old and from Falkirk, Scotland. I've suffered with mental health problems for over 30 years with depression, anxiety and panic attacks, and have been hospitalized a few times now.

In 2004, I was hospitalized for four weeks following a second nervous breakdown. I couldn't explain orally to my partner how bad I was feeling so I started writing it down and it just came out as poetry.

The first poem is "Am I." My partner awoke to read it in the morning and immediately called the doctor. The doctor read it and came over and hugged me saying "it's alright, we'll get you better." He told me he had suffered with mental health issues and had lost 18 months off work because of it, so that was me back in for another three weeks after only being home for a couple of days.

The psychiatrist eventually referred me to a local association for mental health where I joined a writing group. I started to realize that people liked my poetry, and this encouraged me to write more. The second poem, "Barriers" tells of the stigma surrounding mental health issues and was my attempt to raise awareness of this. I also started entering competitions and this led to my work being published in 21 poetry anthology books and several booklets.

The third poem, "The Funny Farm," tells the story of my seven weeks in a psychiatric unit. It was featured in 'Voices,' a film by Bob Owtram that won an international short film award and was shown at the Edinburgh Film Theatre: [https://youtu.be/ocAh\\_I\\_cLGM](https://youtu.be/ocAh_I_cLGM)

Does writing make me feel any better? It does slightly, after all the paper doesn't judge, and if you don't like it you can just bin it. I think a big thing for me though is the fact that "Am I" and "A tale from the damned" both helped me get the help and support that I really needed. "A tale from the damned," the fourth poem, was written a couple of years ago as a suicide note as I'd gotten that ill again that I couldn't even go to my own daughter's wedding; when you already hate yourself that makes it worse. "A tale from the damned" also points to the fact that even though I've suffered with this for over 30 years, I'm still here because if you reach out there is help and support out there.



**Am I? by Glenn Merrilees**

I've sunk to the bottom  
of a pit of despair  
screaming for help  
is there nobody there?

cowering in terror  
trembling with fear  
it's cold and it's dark  
and it's lonely down here.

afraid of a shadow  
I can't even see  
stuck in an eddy  
that's swallowing me.

am I free as an Eagle?  
folk say I look well  
my stomach in turmoil  
my soul in a cell.

can't answer the doorbell  
can't answer the phone  
surrounded by loved ones  
i'm still all alone...

can't express feelings  
that cut me in two  
I take pen to paper  
the best I can do.

far too many questions  
answers far to few  
never looking forward  
as tears obscure my view

try to stagger forward  
my crucifix in tow  
am I gonna make it  
I honestly don't know.

**Barriers by Glenn Merrilees**

there's people throwing insults  
there's people throwing stones  
you cannot see this illness  
no sign of broken bones.

so many nasty comments  
remarks are so unkind  
you cannot see this darkness  
this poison in the mind.

hey look, that guy is mental  
a loony, what a waste  
your bitter twisted comments  
leave an acrid taste.

just remember i'm a victim  
of this pain you cannot see  
depressions made a home in hell  
especially for me.

do not judge this cover  
you simply have to look  
i'm drowning in a sea of pain  
pages missing from this book.

would you berate the lowly cripple  
and call poor soul a name  
my illness needs no crutches  
hang your head in shame.

I do not plead for sympathy  
understanding is the key  
as without this murderous illness  
you're just the same as me.

just show some understanding  
and maybe lend your ears  
then maybe you could save a life  
or stem the flow of tears.  
breaking down the barriers

I try to change your view  
one in four's a victim  
and the next one could be you.

### **The Funny Farm by Glenn Merrilees**

So they took me tae the "funny farm"  
It might hae been at night  
A really can't remember  
Fur a wisnae really "right".

I'm in here, in this "loony bin"  
Seemed no-one outside cared  
Alone and isolated  
Cold, distraught, and scared.

Those people all around you  
They suffer jist the same  
Depression, and anxiety  
Cursed wi a different name.

Alone I sit and wallow  
In a pain you cannot see  
A deep, dark, sad depression  
That gnaws away at me.

You only see the bad things  
You cannot see the good  
A gave up awe ma hobbies  
A gave up eatin' food.

Never ate, a solid fortnight  
Nae breakfast, lunch, nor tea,  
Could only take in liquids  
Enough tae sustain me.

They never even noticed  
Nae appetite tae sate  
Consultant telt ma misses  
That I'd even pit oan weight.

So am locked up in the "funny farm"  
No knowin' who wis who  
People marchin' roond an roond  
Awe dressed the same as you.

One NURSE a verbal bully  
A wish that a could name  
A thing a stood an witnessed  
Like tae pit that git tae shame.

He wis oan the tablet trolley  
A wis standin' in the line  
But his comments tae a patient  
Still chill these bone's "o" mine.

Big laddie, he came runnin'  
His problem couldnae wait  
Poor soul, I saw in pieces  
The next bit does frustrate.

Need something fur ma voices nurse  
The reply was out of order  
The only thing I've got for you's  
A fucking tape recorder.

Seen one nurse, a big strong bully  
Pull a woman through the air  
She was sittin' in the garden  
But he yanked her oot that chair.

Ten folk hud sat an seen it  
That nurse he didnae care  
No the kind "o" treatment  
You'd expect tae get in there.

So a made a sarky comment  
That night, then went tae bed  
Next day, pulled tae the office  
And this is what wis said.

**The Funny Farm by Glenn Merrilees (cont.)**

You never saw the first part Glenn,  
You only saw the end  
There's much mare tae this story  
An whit happened tae yer "friend".

BUT, It's a psychiatric unit!!!  
We're entitled, patient care  
A caring arm around you  
No tae pull ye through the air.

Ten "o" hud saw it  
An some walked aff in tears  
Complaint about a bully  
Hud landed oan deaf ears.

I've cawed the place the funny farm  
But that isn't strictly true  
As some in there would rant and rave  
And scare the breeks aff you.

Schizophrenic or bi polar  
Or some other "mental" name  
An illness thrust upon them  
It isn't them to Blame.

One woman was a princess  
Another man, a Quee  
Hudn,  
Some were just dead scary  
Inside that ward eighteen.

Some geezer oan a trumpet  
But he only played one note  
Another in the corner  
Shakespeare he wid quote.

Others, they seemed "normal"  
But at night you heard their screams  
Past's came back to haunt them  
Nae chance "o" peaceful dreams.

One woman wis a lady  
Hud servants, butlers too  
Went aboot in joggie suits  
AN spoke like me an you.

Another wis a prophet  
His orders came fae God  
Took drugs that make yer mind bend  
An alcoholic sod.

Then there wis the pop star  
Young lassie, near nineteen  
Sixteen worldwide number ones  
Awe ower theworld she'd been.

A wis in a month, then oot again  
Barely in ma door  
Fell tae bits, a jelly  
In fur three weeks more.

Another phase of madness  
Hud dropped, enveloped me  
Crawling through a tunnel  
In which a couldnae see.

There's folk outside That really cared  
But depression, am it's host  
The love that floats around you  
Can't see it, cause yer loast.

### **A Tale From The Damned by Glenn Merrilees**

Lay no flowers on my coffin  
Nor hang your head to weep  
For I have not forsaken you  
I've only gone to sleep.

Place my ashes at the lay-by  
And maybe plant a tree  
And each year when it blossoms

For a moment think of me.

Know how much I loved you  
More and more each day  
My darling that's the answer  
As to why I went away.

The pain that I was suffering  
On my pathway down through Hell  
Burnt my soul in many ways  
But was singeing yours as well.

I love you way too much for that  
I'm sick, recurring pain  
But every time I suffer  
It hits you once again.

I'm useless as a partner  
And I'm useless as a dad  
I gave my children nothing  
Yet It's all I ever had.

I keep on failing everyone  
I'm a nightmare during day  
Like the moon moves in the evening  
It's time to go away.

Yet you my doll were awesome  
For twenty-seven years  
You held me up and comforted  
This endless stream of tears.

So now my time is over  
It's Heaven or It's Hell  
I tried to do my best in life  
But I didn't do too well.



Poems by Glenn Merrilees

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**Global Perspective on Disability Studies****A Theatre Production by Acid Attack Survivors: A Report and Reflection**

Sona Kazemi,  
Mills College

**Abstract**

"From believing in yourself to performance" by three acid attack survivors, Mohsen Mortazavi, Maryam Zamani, and Elham Soltani, with the honorary presence of the professional actress, Shima Khosh Akhlagh. Directed by Javad Rahimi. Executive producer: Payam Ahmadi.

*Keywords:* acid attack, trauma, performance, visibility, arts

### نمایش قصاص هنگام جنایت

«از خود باوری تا اجرا» کاری از کارگاه بازیگری با هنرنمایی محسن مرتضوی، مریم زمانی، الهام سلطانی - سه تن از قربانیان اسید پاشی و یک بازیگر افتخاری، شیما خوش اقبال- بود که مورد استقبال مردم قرار گرفت و تماشاچیان زیادی به خود جلب کرد. این نمایش بعد از شش ماه تلاش و تمرین بی وقفه به نمایش عمومی درآمد و پیام اصلی آن، فرهنگ سازی در جهت تغییر نگاه و رفتار مردم به قربانیان اسید پاشی بود.

در این نمایش، پسری ۳۲ ساله به نام نیما به خاطر مسائل خانوادگی و برای فرار از بدرفتاری‌های نامادری خود از خانه می‌گریزد و به کارهای خلاف رو می‌آورد. عاشق دختری به نام الهام می‌شود. آن دو به رغم مخالفت خانواده‌ها با هم ازدواج می‌کنند. بعد از ازدواج، بدرفتاری‌های نیما و آزار و اذیت‌هایش، باعث نزاع‌های مداوم در خانه می‌شود. این نزاع‌ها با جنایتی هولناک پایان می‌یابد و نیما به صورت الهام اسید می‌پاشد. مادر الهام، معصومه، که سعی در ایجاد آرامش و سازش دارد نیز ناخودآگاه درگیر این جنایت هولناک می‌شود.

مریم زمانی که خود از قربانیان اسیدپاشی و از بازیگران این نمایش است به صونا کاظمی می‌گوید:

«این اولین تجربه بازیگری من بود و خوشحالم که در این نمایش بازی کردم. شریک کردن دوستان و هم‌نوعان و قربانیان اسیدپاشی در این تجربه برایم بسیار لذت بخش بود. وقتی که برای اولین بار توانستم در برابر تماشاچیان ایفای نقش کنم و وقتی با استقبال مردم و تماشاگران روبه رو می‌شدم کلی شوق و ذوق می‌کردم. این خود درسی است به دیگر قربانیان که آنها هم می‌توانند داشته‌های خود را به نمایش بگذارند. امیدوارم با این کار توانسته باشم قدمی نو در راستای خودباوری قربانیان برداشته و تاثیری در رشد فرهنگ مردم در مورد فجایع اسید پاشی گذاشته باشم.»

در آخر برای تمامی قربانیان اسید پاشی آرزوی سلامتی و بهبودی کامل دارم.

«مریم زمانی»

**Vengeance in Crime**

A stage production by Drama Workshop

Featuring three survivors of acid attacks, *From Self-respect to the Stage* production was warmly acclaimed by a large audience. Mohsen Mortazavi, Maryam Zamani and Elham Soltani starred in the play produced by Drama Workshop following months of preparation and rehearsals. The theme of the production is centered on raising awareness on the plight of



victims of acid attacks and helping to fight ableism and change public perceptions.

In this production, Nima is a 32-year-old son facing family conflict including persecution by his step-mother. He leaves home and becomes involved in crime before falling in love with Elham. The couple soon marry despite opposition from their respective families. However their new life is riddled with domestic violence thanks to Nima's abusive behavior. In the end, Nima throws acid on Elham and puts a criminal end to their arguments. Masoumeh, Elham's mother, is unwittingly caught up in this hideous crime despite attempting to bring about peace and reconciliation.

Speaking to Sona Kazemi, Maryam Zamani, herself a victim of acid attack, remarks:

*'This was my first acting experience in a staged production. I was pleased to be a part of this show and share my trauma with friends, audience and victims of acid attacks. It was deeply rewarding to face the applause and appreciation of the audience after my first show. This is a reminder to other victims that they too can showcase their experiences on stage. I hope this production offers a fresh perspective to help victims of acid attacks regain their self-respect and a small step to raise awareness about acid attack tragedies. I wish the best of recovery and health for all acid attack victims.'*

Volunteer Actor: Shima Khosheghbal

Director: Javad Rahimi

Executive Producer: Payam Ahmadi



Image description: A dark background. Once can spot a young woman (Shima Khosheghbal) covered in hijab, sitting on a stool at the back. Lots of bottles with transparent liquid can be seen knocked down. Stools also appear strewn around. Up in the front, Maryam Zamani, a middle-age woman, covered in hijab, can be seen looking down as though she can keenly observe something around the feet of a man in front of her. Her face appears visibly burnt. A younger-looking man (Mohsen Mortazavi) is standing up in front of her a few feet away. He wears a cap, and his face is visibly burnt. He looks away.

Global Perspectives Editors' comment: We are honored to bring this image description for you. Via image description, we discovered our own version of 'access intimacy'. At one end, Sona described the image to Hemachandran, and on the other side, Hemachandran was able to come up with the right description in favor of accessibility.



A Theatre Production by Acid Attack Survivors: A Report and Reflection.  
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## Multimedia

### Book Review: Jasbir K. Puar's *The Right to Maim: Debility, Capacity, Disability*

Ian Hosbach,  
University of North Carolina at Charlotte

#### Abstract

Jasbir K. Puar's 2017 monograph *The Right to Maim: Debility, Capacity, Disability* is a veritable landmark intervention into a number of theoretical fields. Puar is Professor and Graduate Director of Women's and Gender Studies at Rutgers University and obtained her Ph.D. in Ethnic Studies from the University of California at Berkeley. In her analysis of the Israeli state's policies of maiming, predicated on ideological reference to Palestinian homophobia, Puar extends and recontextualizes themes in affect theory, disability studies, queer theory, trans studies, critical race theory, rights-based discourse and activism, posthumanism, and de/postcolonial theory. The work is published by Duke University Press, 221 pages.

*Keywords:* debility, capacity, settler colonialism biopolitics, necropolitics

Jasbir K. Puar's 2017 monograph *The Right to Maim: Debility, Capacity, Disability* is a veritable landmark intervention into a number of theoretical fields. In her analysis of the Israeli state's policies of maiming—policies at least partially predicated on ideological reference to Palestinian homophobia—Puar extends and recontextualizes themes in affect theory, disability studies, queer theory, trans studies, critical race theory, rights-based discourse and activism, posthumanism, and de/postcolonial theory. As Puar states, “the ultimate purpose of this analysis is to labor in the service of a Free Palestine,” a commitment which tragically continues to be necessary in 2021, as the Israeli state continues to ramp up its colonial and genocidal occupation of the Palestinian people and their land (154). Towards the abolishment of this occupation, Puar engages in a thorough analysis of the relationships between settler-colonial logic and the bio/necropolitical control of the nation-state.

I will first give a brief summary of the arguments elaborated in the preface and the six chapters of the book. I will then contextualize the theoretical interventions of the text within the dominant categories of theoretical work and attempt to show that this book works against such compartmentalization. Finally, I will evaluate the strengths and weaknesses of this text and position it as a must read for anyone interested in nuanced analysis of the conditions of possibility for coalitional politics which might actively fight all forms of oppression, and particularly the ongoing oppression of the Palestinian people.

#### Summary

Puar's preface sets up her analysis through the political moment which necessitated its writing. The book finds its roots in the summer of 2014, both in the shooting of Michael

Brown in Ferguson, Missouri, and in the fifty-one day assault on Gaza carried out by Israel and named Operation Protective Edge (ix). The “Ferguson-to-Gaza” approach Puar sees developing within the activism of this period clearly influences Puar’s own formulation of the nature of spatio-temporally dislodged but conceptually and materially connected oppressions and violences, as well as resistances and activism (ix). Following the trajectory of these activisms, Puar’s analysis rejects either/or thinking but also argues that both/and formulations of these struggles fail to resolve the tension between them. Instead, the author mobilizes this tension and makes it productive (xi-xii).

The preface also gives us an important note on Puar’s conceptualization of the books three titular terms: debility, capacity and disability. The author is careful to note that she is not arguing that all bodies are disabled to some degree, nor attempting to replace the concept of disability with those of debility and capacity. Instead, Puar says,

I am arguing that the three vectors, capacity, debility, and disability, exist in a mutually reinforcing constellation, are often overlapping or coexistent, and that debilitation is a necessary component that both exposes and sutures the non-disabled/disabled binary. (xv)

In this framework, the “overkill” of death mobilized against Black communities by police in the U.S. (ix), the repression of protests against the Dakota Access Pipeline (xxiv), the sparing of life (through debilitation) by the Israeli Defense Forces (x), and other struggles, are neither the same nor are they separable. All are fluctuations in the fields of power which mark out and debilitate populations deemed available for maiming. Where debility and capacity are mapped against each other, disability marks a z-axis on which different positions along the gradient of debility and capacity are differentially recognized as deserving of either systems of support, or deserving of their debilitation in the first instance, according to their membership in one population or another (xvii, xxiii).

The introductory chapter is a tour de force in theoretical framing. Most notably, it is in this section that Puar extends her conceptualization the operative analytics of the text *capacity, debility, and disability*. In search of a nuanced disability studies framework for thinking through the emergence of the *right to maim*, Puar introduces the spectrum of debility and capacity as a means for moving beyond the disabled/non-disabled binary (2). Instead, all bodies are positioned on a gradient in relation to two poles—capacity and debility— pure versions of which are impossible (22). This vantage point provides a framework for understanding the relationship between homonationalism, the integration of non-hetero sexualities into the legitimation functions of state power, and the right to maim mobilized by the Israeli state toward Palestinian bodies.

The *It Gets Better* campaign, a global-north-centric narrative of inclusion for non-hetero subjectivities, is read as a capacitation mechanism wherein the market, rather than the state, is produced as the site of redress for queer subjects (7-9). Extending this capacitation mechanism to disability rights activism, Puar argues that the disability rights mode of

inclusion constitutes a reclamation of white privilege (10, 15). In this sense, the moving of bodies which are identified as capable of re-capacitation—bodies in certain intersectional positions—into spheres of profitability and productivity functions to exclude those bodies which are incapable of re-capacitation—colonial, raced, and transgressively gendered bodies—displaced both spatially and temporally (9, 15, 22).

Chapter one then builds on this analysis in order to frame contemporary trans rights discourse which assumes a linear, teleological narrative of civil rights progress (33). Against this, Puar analyzes the Americans with Disabilities Act and its exclusion of trans and gender non-conforming sexualities as a moment which produces conflict between disability and trans rights activism (37-40). Within these two discourses, there seem to be divergent tendencies in theorizing the body. Where disability rights discourse must exceptionalize bodily transgression and survivorship, trans rights discourse sees the body as “endlessly available for hormonal and surgical manipulation and becoming, a body producing towards ableist norms,” (42). Puar notes two vectors of *becoming* in relation to trans discourse. Trans-becoming marks a capacitation of the body which seeks inclusion in logics of privilege—raced, gendered, and abled (56). Becoming-trans, however, produces attentiveness to the multiplicity of self-constitution and bodily difference which works against the very foundations of privilege (56).

Chapter two traces the production of disability ‘elsewhere’ by the colonial metropole (the U.S.) both temporally and spatially—the accident prone, and the foreign, respectively (92). The most notable intervention in this chapter follows Deleuze and Guattari’s critique of the accident in its two main forms: the work myth, and the war myth. Puar says it best,

Fusing these two together—the work myth and the war myth—Deleuze and Guattari insist on the utility of what they call “pre-disabled people” to the braided operations of capitalism and the war machine of the state. Mutilation and amputation are thus no accident but are part of the biopolitical scripting of populations available for injury, whether through laboring or through warring or both: laboring in the service of war that mutilates both national bodies and foreign entities denoted as enemies; or laboring as an inverted form of warfare against a disposable population ensnared as laborers-consigned-to-having-an-accident. (64)

Puar mobilizes this formulation to frame the inclusion-through-exclusion of the Palestinian and disabled populations from narratives of human rights and liberal freedom (72). In this sense, debility reveals a missing component in biopolitical analysis: how disability comes to frame the historical production of populations as such (69).

Chapter three then focuses on the mobilization of this logic in the Israeli state’s relationship to Palestinians, producing disability in the West Bank and Gaza in order to capacitate the Israeli state as able-bodied (101). The Israeli state redirects the fear of being debilitated at the hands of the (homophobic) Palestinian other into the debilitation of Palestine through damaging Palestinian infrastructure and maiming Palestinian bodies (107).

The resultant policy of maiming is made productive not only through the material damage to Palestinian agency, but also through appeal to humanitarian logics of less-lethal warfare. Puar argues,

The consequence of believing that disability is worse than death is simple: “not killing” Palestinians while rendering them systematically and utterly debilitated is not humanitarian sparing of death. It is instead a biopolitical usage and articulation of the right to maim. (108)

Israeli pinkwashing produces the Israeli gay citizen as not-Palestinian, not-Arab, able-bodied, and child-rearing (117, 125). At the same time, the Israeli imposition of “mobility disability,” through occupation and its network of checkpoints, precludes the possibility of LGBTQ+ organizing within Palestine (111, 120).

Chapter four and the postscript then take this right to maim and elaborate not only its value as an analytic within the Israeli-Palestinian context, but also as a corrective within bio/necropolitical theoretical frameworks. Mapping the development of the right to maim from the breaking of stone-thrower’s arms during the first intifada, Puar shows that the target of the right to maim is nothing less than the Palestinian capacity to resist (129, 152). Furthermore, the right to maim undoes the four-quadrant analysis of bio/necropolitics as they are derived from Foucault and Mbembe. In common usage, these four quadrants are “make live,” “make die,” “let live,” and “let die.” Puar’s analysis complicates this framework,

The sovereign right to maim implicates all of the other vectors at once—make die and make live (because in some cases debilitation can be harnessed into “compliant” disability rehabilitation), as well as let live and let die, aversion of slow death, a gradual decay of bodies that are both overworked and underresourced. (139)

In this sense, the right to maim produces a vector that Puar identifies as “will not let/make die”—the actions of the Israeli state are legible as “letting live” and thus are available to discourses of humanitarianism while continuing to debilitate the agency of Palestinian actors (139, 140).

This analysis, however, is not one of totalizing power. Puar notes that the “biopolitical fantasy” of debilitating the Palestinian population’s resistant capacity is just that—a fantasy. What this text does, then, is tie together the fight against ableism, heterosexual patriarchy, settler colonialism, U.S. police violence and Israeli occupation. Puar argues that, “collective punishment is overturned into otherwise untenable lines of solidarity” (160). Anti-occupation activism constitutes a point of convergence for a number of otherwise disparate activisms. The fight against occupation is necessary for any of these activisms to obtain their goals, and without ending occupation, none will succeed (161).

### Contextualization

Puar's text arrives within feminist theory mainly in the vein of transnational feminist critique, articulating the often-universalizing frameworks of feminist disability studies, queer theory and trans studies to material conditions and dynamics of populations that are systematically overlooked. In this case, Puar's analysis of the Israeli state's right to maim, and the production of disability, which is its result, complicate the rights-based activism on which so much of contemporary disability and LGBTQ+ activism is built. From this perspective, Puar complicates the *subject* of each of these discourses in relation to the mechanisms of power which exclude them. These *subjects* are revealed to have been afforded untenable individuation and essence. In this sense, Puar's work can be categorized within strains of affect theory, queer theory, and feminist disability studies which draw from post-structuralist discourses of power and subjectivity production. Her work might be situated within the affective turn which resists overdetermination of subjects by the discourses in which they live, arriving at affect as a site of collision between individual experience and discursivity.

Puar works, in this text, at the intersections of Foucauldian biopolitics, Mbembe's necropolitics, and Deleuze's analysis of control societies. However, I think this categorization not only does injustice to the breadth and depth of Puar's analytical insight, but itself reifies the taxonomic impulse which Puar's analysis works against. Puar produces complications for not only these genealogies of thought, but also for the focus on genealogical categorization in academic discourse. Yes, she works with post-structuralist authors at length, but her analysis is not the cookie-cutter imposition of these theories to material conditions. Instead, Puar shows how the nuances of material conditions of trans discourse, disability activism and Palestinian struggle for self-determination push and pull each other. They extend and complicate each other, but ultimately, they also enrich each other in such a way that their dissolution seems unproductive, if not untenable.

### Evaluation and Conclusion

This book is a must read for those working within post-structuralist analysis, analysis of the qualitative turn of neoliberal power, as well as analysis of global south activism within disability, trans, queer, and class contexts. Her analysis adeptly navigates structures of power from the level of policy to that of everyday movement. However, this produces a book that is intricately dense. Every sentence feels as though it is about to burst into a paragraph—*or two*—and sometimes that explosion is sorely missed. Here is the largest obstacle between this text and its intended goal. In analyzing the imbrication of so many oppressions, socio-cultural fields of power, and histories of discourse, the book approaches the limit of density where its articulation with the practical political project of a Free Palestine collapses in on itself. Puar develops and extends analysis from a host of other theorists, past and contemporary, always with an eye towards conviviality, even if generous readings are hard to produce. This thoroughness in relation to those on whom her work builds makes for an exceedingly nuanced argument, but also makes the book an intensely laborious read: only time will tell its role in the movement it expressly supports, but the strength of its analytical insight is

undeniable.


For example, her commitment to rigorous analysis of ideological content Puar deftly articulates advertisements for Israeli inclusion of homosexual soldiers with their simultaneous violent debilitation of queer Palestinians (98). Her ability to juxtapose ideological positions with their material effects produce a stunning portrait of the insidiousness of contemporary bio/necropolitical control. Puar remains committed to something like bottom-up theorization, however, the separation of the ideological from the material is revealed to be untenable. The ideological is revealed to be always already material in its causes and effects.

In closing, Puar's analysis is heavy. It weighs down the purported humanitarianism of less-lethal control policies with the horrors they legitimate. Puar's project evades the limitations of rights-based discourse through analysis of the privileged subject positions for whom it is available as recourse, even if the gains attained by global-north rights-based activism are not the focus of this project. Most importantly, however, it ties down theoretical strands which are historically vulnerable to being blown sky-high, that is, away from the material conditions in which they are grounded. It tethers theory to its political articulations. Puar makes explicit her unabashed support for Palestinian struggle, towards which this analysis is carried out. When disability, queer and trans activism are foregrounded, they are never introduced as metaphor, nor are they divorced from their context and made universalizing. They are, however, articulated with Palestinian struggle towards a coalitional opposition which takes oppression, as such and in all its forms, as its object of action.

This coalitional approach is invaluable for those in the United States in this historical, political moment. As police brutality continues to kill black people, uprisings against this brutality have faced something akin to, if not another materialization of, the right to maim which Puar lays bare in this text. The deployment of both tear gas, during a pandemic which targets respiratory functions, and rubber bullets which break arms and cause internal organ damage are certainly presented as soft versions of control. Furthermore, the liberal centrism of the Democratic Party has done nothing to redress the U.S. funding and cooperation which is integral to the ongoing Israeli violence against Palestinians. Puar's analysis reveals the ways in which sub-U.S. populations might be targets of a domestic right to maim and how the U.S. government is implicated in its exercise in Palestine. In any case, Puar has produced an invaluable insight into contemporary state violence, and its legitimation functions.

### References

Puar, J. K. (2017). *The right to maim: debility, capacity, disability*. Duke University Press.

 Book Review: Jasbir K. Puar's *The Right to Maim: Debility, Capacity, Disability* <https://rdsjournal.org/index.php/journal/article/view/1050> is licensed under a [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/). Based on a work at <https://rdsjournal.org>.



## Notes from the Field

### Disability and Diversity Calendar: Calls, Awards, Conferences

Genesis Leong,  
Center on Disability Studies, University of Hawai'i at Mānoa

**Abstract:** To support the growth of disability and diversity research, scholars, advocates and community members, the following document includes a list of upcoming opportunities:

- Call for Participation, Presentations, Publications, etc.
- Awards, Fellowships, Internships, Mentorships, Scholarships, etc.
- Conferences, Webinars, etc.

This resource was compiled by the Center on Disability Studies, University of Hawai'i at Mānoa. If you have a call, award or conference/event you would like to include in the next issue, please submit a request to <https://rdsjournal.org> in the 'Notes from the Field' category. No additional fees are required.

#### Call for Participation, Presentations, Publications, etc.

##### June 4, 2021

#AUCD2021 Conference - seeking conference proposal reviewers <http://bit.ly/061CDS>

##### June 11, 2021

#AUCD2021 | Learning Together: Connecting Research and Lived Experience - accepting concurrent and poster presentations proposals <http://bit.ly/062CDS>

##### June 13 , 2021

D-30 Disability Impact List - seeking nominations to honor people with disabilities globally making a difference in their community <http://bit.ly/063CDS>

##### June 14 , 2021

National Advisory Committee on Individuals With Disabilities and Disasters - search for members to provide recommendations to the Secretary of HHS <http://bit.ly/064CDS>

##### June 15, 2021

Research in Social Science and Disability: Disability in the Time of Pandemic - accepting abstracts to contribute to the 2022 chapter publication <http://bit.ly/065CDS>

##### June 20, 2021

SDS Student Representatives Board of Directors: Society for Disability Studies - seeking nominations to serve the 2021-2022 term <https://disstudies.org>

SDS Board of Directors: Society for Disability Studies - seeking nominations to serve for three years <https://disstudies.org>

**June 25, 2021**

IOD Institute on Disability Calendar: Call for Artists - accepting artwork for the 2022 calendar <http://bit.ly/066CDS>

**June 30, 2021**

VSA Arts Connect All - nine RFPs available for proposals that provide accessible, arts-based education experiences/transition to students with disabilities, or educators  
<http://bit.ly/067CDS>

**July 14, 2021**

World Disability and Rehabilitation Conference - accepting proposals highlighting the theme 'It Takes a Village' Accessing Disability Services Across the Globe <http://bit.ly/068CDS>

**July 15, 2021**

Western History Disability Studies and Disabled Scholar Award - award applications to receive assistance to present academic papers <http://bit.ly/069CDS>

**July 16, 2021**

'Ohana Engagement Conference Presenter Proposal - accepting Hawaiian cultural-based proposals to present <http://bit.ly/075CDS>

**July 30, 2021**

You're On! 2021 Artist Spotlight - seeking submissions from artists of any age who are on the autism spectrum or who have a sensory or low-incidence disability <http://bit.ly/076CDS>

**July 31, 2021**

AUCD Multicultural Council Chair and Secretary - seeking members to join the Executive Committee <http://bit.ly/070CDS>

**Aug. 31, 2021**

Rethinking the Species Divide: Disability and Animality in Literature and Culture- accepting submission to publish in the Journal of Literary and Cultural Disability Studies  
<http://bit.ly/071CDS>

**Sept. 13, 2021**

Early intervention in Developmental Disabilities - accepting submissions to publish in the Research In Developmental Disabilities Journal <http://bit.ly/072CDS>

**Sept. 14, 2021**

Research Paper Summaries: Diversity, Equity, and Inclusion | Seen@Work - accepting submissions to publish <http://bit.ly/073CDS>

Study Proposals: Diversity, Equity, and Inclusion | Seen@Work - seeking research proposals  
<http://bit.ly/074CDS>

**Sept. 15, 2021**

Disability as Diversity | The Journal of Teaching Disability Studies - accepting proposals to publish <http://bit.ly/077CDS>

**Sept. 30, 2021**

Racial and Social Justice - accepting papers to publish in the PNAS Proceedings of the National Academy of Science of the USA <http://bit.ly/078CDS>

**Oct. 31, 2021**

Physical Activity, Exercise and Fitness - accepting submissions to publish in the Journal of Intellectual Disability Research Special Issue, visit <http://bit.ly/079CDS>

**Oct. 31, 2021**

Enhancing Research Practice in Developmental Disabilities - accepting submission to publish in the Research In Developmental Disabilities Journal <http://bit.ly/080CDS>

**Nov. 1, 2021**

Spirituality and Disability Symposium - accepting papers to present on April 8-9, 2022 <http://bit.ly/081CDS>

**Awards, Fellowships, Internships, Mentorships, Scholarships, etc.****June 4, 2021**

AEA Minority Serving Institution (MSI) Fellowship - seeking applications to participate in the MSI Faculty Initiative program, visit <http://bit.ly/082CDS>

**June 15, 2021**

East-West Center Student Affiliate Program - seeking UHM graduate students with an interest in the Asia Pacific region to participate in the program, visit <http://bit.ly/083CDS>

**June 2021**

2021 Disability Research Mentorship Program for Black Graduate Students - seeking applications to participate in a mentorship program. Applications are being accepted on a rolling basis until positions are filled <http://bit.ly/084CDS>

**July 1, 2021**

Fellowship in Disability and Health Policy - seeking applicants to participate in the Lurie Institute Postdoctoral program, visit <http://bit.ly/085CDS>

**July 14, 2021**

Heumann-Armstrong Award - seeking to award \$1,000 to six students (6th grade to higher education) willing to be interviewed on their experience with ableism in education <http://bit.ly/086CDS>

**Aug. 1, 2021**

Native American & Indigenous Studies (NAIS) Writing & Mentoring - seeking applicants to participate NAIS mentoring program, visit <http://bit.ly/087CDS>

**Sept. 17, 2021**

2021 Henry Viscardi Achievement Awards - accepting nominations that recognize exemplary leaders with disabilities, visit <http://bit.ly/088CDS>

**Conferences, Webinars, etc.****June 2-30, 2021**

NADP-UK International Conference - offered virtually over the 5 weeks of June by the National Association of Disability Practitioners <http://bit.ly/112CDS>

**June 3, 2021**

Re-Storying the Ramayana: A Role-Playing Game - an interactive virtual reimagining of the South Asian epic as a queer/crip ecofeminist sci-fi tale <http://bit.ly/092CDS>

**June 7-10 or 27-30, 2021**

Teaching to Increase Diversity and Equity in STEM (TIDES) - online conference by the Association of American Colleges and Universities <http://bit.ly/093CDS>

**June 7-11, 2021**

NCORE 2021: Start the Conversation - online conference by the National Conference on Race and Ethnicity in American Higher Education <http://bit.ly/095CDS>

**June 7-11, 2021**

ADA National Network 30th Anniversary Series: Spotlight on the ADA Participatory Action Research Consortium - webinar <http://bit.ly/094CDS>

**June 8-11, 2021**

Edu Data Summit: Intersection of Big Data, Predictive Analytics, Learning Analytics, and Education - virtual conference <http://bit.ly/096CDS>

**June 9, 2021**

Reimagining a child welfare system that works for parents with disabilities and their families - online conference by the National Research Center for Parents <http://bit.ly/103CDS>

**June 9-10, 2021**

State of the Science: National Research Center for Parents with Disabilities - online conference will address disability and parenting <http://bit.ly/099CDS>

**June 9-11, 2021**

5th International Conference on Universal Design - online conference by the Aalto University <http://bit.ly/098CDS>

**June 10, 2021**

Early Identification of Autism: Training on the RITA-T (Rapid Interactive Screening Test for Autism in Toddlers) - registration \$75 and kit \$85 <http://bit.ly/104CDS>

**June 14-18, 2021**

APSE Annual Conference - [conference] Illuminate: Lighting the Path Forward for Employment First <http://bit.ly/106CDS>

**June 16, 2021**

State of the Science: Reflections from Advisory Board Members - online conference by the National Research Center for Parents <http://bit.ly/099CDS>

**June 18-19, 2021**

2021 Sibling Leadership Network National Conference Program - 'Strength Through Connection' will examine siblings of people with disabilities <http://bit.ly/108CDS>

**June 22, 2021**

Supporting Teachers' Use of Assistive Technology in Early Childhood: Lessons Learned in a Post-Pandemic World - webinar sponsored by the AUCD Early Childhood SIG <http://bit.ly/115CDS>

**June 22-23, 2021**

AAIDD 145th AAIDD Annual Meeting - conference 'Addressing Workforce Challenges: Promising Trends in Policy, Practice, and Research' <http://bit.ly/113CDS>

**June 23, 2021**

Opportunities with the National COVID Cohort Collaborative - discussion on U.S data and opportunities for collaborative research within AUCD <http://bit.ly/116CDS>

**June 25-26, 2021**

Disability, Media, and What's Next: A Conversation on for Disabled Media Makers - virtual conversation on disability, the media, and what's next <https://bit.ly/3uJMeE3>

**June 29, 2021**

Think College: Lessons Learned from a Decade of Data - webinar on a decade of TPSIDs data collection and evaluation <https://bit.ly/34GDRhZ>

**June 29, 2021**

Long Haulers: Post-Acute Covid-19 Syndrome: the Aftermath of Cognitive Disability - webinar 12 - 1:30 PM EST <https://bit.ly/3uLFPbF>

**Tuesday's**

AUCD Tuesday with Liz - a weekly video series highlighting current issues in disability policy. Hosted by Liz Weintraub <http://bit.ly/117CDS>

**July 10-12, 2021**

Disability Studies Conference 2021 - 'Disability Studies, Disability Justice: Challenging Ableism' Auckland, New Zealand <https://bit.ly/2SW4IUQ>

**July 12-15, 2021**

Disability:IN Conference - 'Are You In?' corporate disability inclusion event  
<https://bit.ly/2SPGc7M>

**July 17, 2021**

AHEAD Summer Webinar Series Part 2: Working with Students on COVID Accommodations - 3 - 5pm ET <https://bit.ly/3fMXWK2>

**July 21, 2021**

2021 Autism CARES Grantee Meeting: Committing to Health Equity Across the Lifespan - webinar 2 - 5pm ET <https://bit.ly/2TxBFa9>

**July 22-23, 2021**


TechSummit 2021 - virtual conference with a focus on technology as it relates to developmental disabilities <http://bit.ly/114CDS>

**July 19 - 23, 2021**

AHEAD 2021 Equity & Excellence Conference - in-person or virtual professional development and networking event <https://bit.ly/2SUgn6z>

**Nov 15-17, 2021**

#AUCD2021 Conference - online conference 'Learning Together: Connecting Research and Lived Experience' <https://bit.ly/3g35nvj>

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## Notes from the Field

### Disability Activism and Advocacy Resources:

#### Blog:


### **We Can Do This: Promoting effective engagement related to issues that affect people with disabilities.**

Patricia Morrissey,  
United States International Council on Disabilities

In 2013, I began writing a blog – [www.wecandothisifwetry.blogspot.com](http://www.wecandothisifwetry.blogspot.com). Initially the blog was to promote Senate ratification of the U.N. Convention on the Rights of Persons with Disabilities. When that didn't happen, I broadened the focus of the blog to promote effective engagement on issues that affect people with disabilities. After eight years, I have had 113,000 plus views. The first 80 plus posts I published as a book – *A Moral Imperative: U.S. Ratification of the Convention on the Rights of Persons with Disabilities* – free from Amazon if you have a Kindle.

My most recent post – *Disability Matters, Why Isn't It Counted?* <http://wecandothisifwetry.blogspot.com/2021/06/disability-matters-why-isnt-it-counted.html> – is critically important. Its premise is this -- Those who are disabled and those who advocate for disability rights must realize unless we push for disability-related data collection in all contexts aggressively, we will remain an afterthought and marginalized in the current social push for equity in health care, treatment by police, voting access, and other circumstances. I welcome your taking a look at the blog post. We all need to get involved in data collection.

About Pat Morrissey: President of the Board of United States International Council on Disabilities. Dr. Morrissey was Director, Center in Disability Studies, University of Hawaii, Manoa from September 1, 2016 till last August. Prior to that, she worked in Washington D.C. and held numerous senior positions in Congress and the Executive Branch.

 “Disability Activism and Advocacy Resources: Blog: We Can Do This: Promoting effective engagement related to issues that affect people with disabilities. <https://rdsjournal.org/index.php/journal/article/view/1094> is licensed under a [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/). Based on a work at <https://rdsjournal.org>.

## Notes from the Field

### GOVERNOR APPOINTS DR. KIRIKO TAKAHASHI TO HAWAI'I STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Genesis Leong,

Center on Disability Studies, University of Hawai'i at Mānoa

News Release

**Honolulu, Hawai'i** - On March 31, 2021, the Hawai'i Senate voted to approve Governor David Ige's recommendation (GM581) to appoint Dr. Kiriko Takahashi to serve as a member of the Hawai'i State Council on Developmental Disabilities (DD Council).

Effective immediately until June 20, 2022, she will join the 28 Governor appointed members that include individuals with intellectual and developmental disabilities, parents, family members and representatives from public and private agencies that serve this population. Established by state and federal law as an independent agency, the mission of the DD Council is to empower, advocate, and support individuals with intellectual and developmental disabilities statewide to control their own destiny and determine the quality of life they desire.

Dr. Takahashi is the current director of the Center on Disability Studies (CDS), University of Hawai'i at Mānoa. CDS is one of 67 University Centers for Excellence in Developmental Disabilities (UCEDD), education, research, training centers across the U.S. and its territories. It is uniquely positioned within the University and extended community to work towards a shared vision of a nation in which all Americans, including those with disabilities, participate fully in their communities.

The DD Council is CDS's sister agency, and our work is authorized under Public Law 106-402 per Developmental Disabilities Act of 2000. Therefore, as a council member, Dr. Takahashi hopes to be informed about the current needs of individuals with intellectual and developmental disabilities to continue the Center's programming. She also hopes to provide input to the DD Council's 5-year plan, help monitor their implementation, and collaborate together on integrating the lives of people with intellectual and developmental disabilities at community and systems level across the lifespan.

For more information on Dr. Takahashi's appointment or the Hawai'i State Council on Developmental Disabilities, contact Daintry Bartoldus, Executive Administrator, [daintry.bartoldus@doh.hawaii.gov](mailto:daintry.bartoldus@doh.hawaii.gov), (808) 586-8100.

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*The Center on Disability Studies, University of Hawai'i at Mānoa is a research center aimed to promote diverse abilities across the lifespan through interdisciplinary training, research*



and service. For more information visit [cde.coe.hawaii.edu](http://cde.coe.hawaii.edu), or follow us on Twitter [twitter.com/CDSHawaii.edu](https://twitter.com/CDSHawaii.edu) and Facebook [www.facebook.com/CenterOnDisabilityStudies](http://www.facebook.com/CenterOnDisabilityStudies).



Governor Appoints Dr. Kiriko Takahashi to Hawai'i State Council on Developmental Disabilities <https://rdsjournal.org/index.php/journal/article/view/1077> is licensed under a [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/). Based on a work at <https://rdsjournal.org>.

## Notes from the Field

### Hello from PHAME Academy

Jenny Stadler,  
Portland, Oregon

Hello from Portland, Oregon—we're PHAME! We're a nonprofit that empowers adults with intellectual and developmental disabilities. Founded in 1984, we now serve upwards of 120 students per year. In addition to offering ten-week terms of arts-based classes throughout the year, we also have a rigorous performance program that puts our students in front of audiences across the Portland metropolitan area and beyond. Our organization is built on the belief that art is for everyone, and that our community is stronger when everyone has the chance to pursue their own creativity.

The pandemic forced us to close our campus and pivot to online programming, but thanks to the ingenuity of our staff and students, PHAME is thriving. Since moving online, we've held more than 120 classes, free online hangouts, visiting artists, drop-in meditation sessions, and much more. We're now in the early stages of planning a return to in-person class offerings, but one thing we've learned from this year spent online is that for many people with disabilities, online can be the preferable—or only—way to participate. So online classes will be a part of PHAME for the long run.

PHAME's future is looking bright: we're continuing to expand our partnerships with local arts orgs, we're making multimedia video projects this summer, and in 2022 we plan to present an original play written and designed by PHAME artists.

We'd love to hear from you if you're interested in learning more, or have expertise to share in program evaluation or digital arts. Please reach out, or follow our progress as we shift to a hybrid model of in-person and online classes, by visiting [www.phamepdx.org](http://www.phamepdx.org).

A work produced by PHAME Students:

Lost in the Woods, duration: 2 minutes 23 seconds

Link to video: <https://youtu.be/MgCD7Vuzuak?t=143>

About the project: What happens when Hulk the Dog runs into an enchanted wood, leaving his friends to come and find him? The answer includes a haunted fun house, myriad ghosts, and a little romance. This is the premise of [Lost in the Woods](#), an animated original short produced entirely online by PHAME students and staff in the summer of 2020. Part poetic storytelling and part visual revelry, this video illustrates the talent, creativity, and artistry of PHAME students.

In the summer of 2020, PHAME held three separate classes that each met twice a week for 9 weeks to create this video. They were: line drawn animation (8 students), poetic storytelling (5 students), and musical storytelling (10 students). The poetic storytelling class wrote the story told in the video, and then it was animated by our animation students and

scored by our musical storytelling students. In addition, selected voice acting students recorded the voices of the characters. All of this work was guided by our teaching staff, as it was a student project, and the sound mixing was done by a staff member. But the final edit was a collaboration between teaching artists and students, and all of the ideas, poetry, drawings and musical motifs came from our students.

The final editing took place in the three weeks after the class term ended.



Hello from PHAME Academy

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## Notes from the Field

### Call for Proposals Special Issue: Disability and Film and Media

Beth A. Haller, Towson University  
Lawrence Carter-Long, Disability Rights Education and Defense Fund

DUE: August 15, 2021 at [rdsjournal.org](http://rdsjournal.org)

Film and Media can play a profound role in the ways in which cultures both reflect and develop their understandings of identity. The ways in which disability is imagined on the screen can have real impact on efforts for inclusion in a variety of domains in the real world. In the wake of the success in recent years of social justice movements like Black Lives Matter and #MeToo, there is increasing international attention to disability rights and activism. There is also increasing concern about equity on screen, both in terms of the presence of characters as well as opportunities for performers.

This special issue will be devoted to considering Disability and Film and Media. Guest editors will be renowned media scholar Beth Haller (Towson University) and noted film scholar, historian and activist Lawrence Carter-Long (Disability Rights Education and Defense Fund DREDF). Questions may be addressed to [rdsj@hawaii.edu](mailto:rdsj@hawaii.edu).

For this conversation about representation of disability in film and media, work from both academics and non-academics will be welcomed. Topics may include:

- Representation in TV, film, or other media forms
- Disability, film, media and equity
- Portrayal of characters with disabilities by nondisabled actors
- Intersectional and/or cross-cultural analysis
- Historical contributions
- Regional profiles
- Statement by artists (including film and media makers and actors)
- Reception studies
- Alternative disability aesthetics
- Disability and Oscars (and other awards)
- Disabled star profiles
- Disability and genre
- Disability and news
- Disability and social media
- Disability and Children's media

### Guest Editors


Beth A. Haller is a professor of mass communication and communication studies at Towson University, specializing in the handling of disability in news and new media. She serves on the advisory board of the National Center on Disability and Journalism, and traveled in

Australia as a Fulbright Scholar in 2015. Books by Haller include *Representing Disability in an Ableist World* (2010) and *Byline of Hope: The Newspaper and Magazine Writing of Helen Keller* (2015).

Lawrence Carter-Long is the Director of Communications, Disability Rights Education and Defense Fund (DREDF). A lifelong activist, he currently spearheads the Disability & Media Alliance Project. Lawrence has been a modern dancer, radio show host and producer, and was the curator/co-host of groundbreaking festival “THE PROJECTED IMAGE: A HISTORY OF DISABILITY ON FILM” on Turner Classic Movies reaching 87 million people. His advocacy has been awarded by former NYC Mayor Mike Bloomberg, the American Association of People with Disabilities, and others.

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*The Review of Disability Studies: An International Journal, an online quarterly journal published by the Center on Disability Studies at the University of Hawai‘i at Manoa, invites advertisements from (a) publishers of books, films, videos, and music, (b) disability related organizations or event coordinators, and (c) producers and distributors of products and services. For questions or inquiries, please email [rdsj@hawaii.edu](mailto:rdsj@hawaii.edu) or visit <http://rdsjournal.org>*

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## Notes from the Field

### Course Announcement: Literary and Cultural Disability Studies: An Exploration

Hemachandran Karah,  
IIT Madras

#### BACKGROUND

As a field of enquiry, Literary and Cultural Disability Studies (LCDS) is concerned with how disability and other human conditions mediate our connection with cultural artefacts such as literature. This exploratory course on LCDS has 4 modules, namely disability and canon, literary criticism, the multilingual question, and interdisciplinarity. All 4 modules entertain a curious mixture of lectures, conversations with specialists from India and around the globe, and classroom discussions. Such a mixture may come in handy for learners in relishing myriad cultural debates surrounding disability, as much as its treatment as an interpretative method.

#### INTENDED AUDIENCE:

- Students pursuing Masters in Humanities and Social Sciences
- Scholars engaged in doctoral and postdoctoral research In Literature and Cultural Studies
- Anyone who is willing to pursue Disability Studies beyond the basics

#### IMPORTANT DATES:

Duration : 12 weeks

Start date: 26 Jul 2021

Enrollment ends: 2 August 2021

#### COURSE AND FEE DETAILS

The course is free to enroll and learn from. There may be a nominal fee for those who wish to register for the course outside India. For more information, kindly visit: <https://tinyurl.com/hznepdzc>

#### INSTRUCTOR BIO

Dr. Hemachandran Karah teaches English Literature at the Humanities and Social sciences faculty, IIT Madras. He is interested in researching on themes such as disability, health, the language question, literary criticism, and musicology. Please find further details here:

<https://iim.academia.edu/HemachandranKarah>



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