Building Legacies of Health and Healing - TRANSCRIPT

Katherine Fusco, Ph.D.

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Hello and welcome to our next installation of *Though on Tap.* Your guide to news, views and brews. I'm Catherine Fesco the director of the Core Humanities program and before we get started with tonight's topic which is building legacies of health and healing. I want to say a couple of thank yous and then introduce you all to our panelists for the evening. So first I want to thank our sponsors the College of Liberal Arts at the University of Nevada, Reno, the core humanities program, and the Laughing Plane.

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Which is where we would normally be holding these events and so we are really looking forward to getting back to the Laughing Planet, when we're able to be live and together, but you should still go get delivery from the Laughing Planet have some of their of their delicious bowls, and we will look forward to seeing you there. When we can be back. And I also want to say thank you to Chris Stancil, to Carlos Mariscal, to Bretton Rodriguez and Richie Bednarski, all of whom are helping out behind the scenes

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At the end of our event tonight, please do take a moment to fill out the survey that will pop up. That helps us know what we're doing well, how we're doing delivering this online programming and good stuff like that. Also throughout the event tonight you can put questions for the panelists into our Q&A and we'll work to get your questions answered by our wonderful group of panelists, so I'm going to introduce tonight's topic and then introduce our panelists and

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then we'll have our wonderful discussion. So, the panelists for this installation of thought on tap, consider the human relationship to health and well being, considering topics such as how individuals process trauma, the way we move in and out of ability and disability over the course of our lifetimes. And the way this affects our self conception, as well as how marginalized and at risk communities advocate for their health when the larger society turns its back.

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Perhaps no year has brought these issues more to the fore than the one we've just gone through and in many ways are continuing to live in. We've seen differential distributions of the health, health effects of COVID-19, and as an article published on Health Affairs notes communities of color, including African Americans Hispanics and Native Americans are more likely to suffer serious effects and die as a result of complications from COVID-19 and the article goes on to say people of color are typically

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disproportionately under insured, with less access to high quality treatment and preventative care. As a result of these long standing systemic social and resulting health inequalities racial and ethnic minority groups of all ages have higher rates of untreated asthma, obesity, diabetes and heart disease. So we've seen a lot to make us very concerned about health and well being and the way that it is unevenly distributed in many ways, as well as the way illness can uneven effects.

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But in many ways COVID has just made manifest something that lots of folks have known all along that illness is not evenly distributed nor is care. And so we've also heard stories from people living with disabilities this year that speak to anxieties about how we as a society value the lives of those who have a medical disability and denote the valuation of the lives of the elderly and the elderly poor who may be living in care homes. The virus has raised a lot of questions about how we as a society, think about health as both an individual and the collective issue.

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In this semester's *Thought on Tap* series we're moving towards hope. And one of the things that we've seen that looks like hope is the way that communities have advocated for themselves, and the kind of education we've seen as a nation about the ways health and healing, can be social, political and historical issues as well as scientific ones. Tonight we have three excellent panelists to help us think through issues of identity, self perception advocacy and health and healing. I'll introduce them one by one.

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And then I'll start us off with a few questions but I hope that you all will contribute your own questions using that Q&A function. So first, it's my pleasure to introduce Melanie Duckworth, who is an associate professor in the Department of Psychology and an associate dean of the College of Science at the University of Nevada, Reno. In her administrative role she supports the academic success and career readiness of graduate and undergraduate students across the college, she directs the women in science

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and engineering program and supports academic and personal wellness programming occurring in the WISEs, the women in science and engineering and College of Science Living and Learning Communities. In her faculty roll doctor Duckworth directs the health and traumatic injury research program, where she conducts laboratory based and clinical research that examines the pre-peri and post-collision variables that predict post collision physical and psychological recovery, and overall quality of life.

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She’s published peer reviewed journal articles and invited book chapters and has served as a lead editor for three internationally disseminated books addressing physical injury and psychological trauma. Most recently dr Duckworth co edited prejudice stigma privilege and

oppression of behavioral health Handbook, a book that examines the way in which clinical psychologists conceptualize and respond to the prejudice and oppression that their clients experience in their lives and poses solutions to the problem of underrepresentation of culturally diverse groups among professionals in the field of psychology, Dr. Duckworth was the Associate Dean of diversity inclusion for the College of Liberal Arts prior to transitioning to the College of Science.

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In that role, she conducted faculty development leadership workshops, addressing issues of diversity, equity and inclusion and co lead the Northern Nevada women's lead Leadership Initiative, a collaborative project sponsored by the College of Liberal Arts and the Reno-Sparks Chamber of Commerce. Dr. Duckworth received her doctorate in clinical psychology from the University of Georgia and completed an APA approved pre-doctoral internship, through the Brown University psychology internship Consortium, and the National

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Heart, Lung and Blood Institute funded postdoctoral fellowship, through the Brown University School of Medicine. So welcome Dr. Duckworth.

Dr. Melanie Duckworth

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Thank you for having me here. It's delightful to be with all of you, and I'm excited about being on the panel.

Katherine Fusco

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And next we have Dr. Emily Hobson who has a joint appointment in the Department of History and the Department of gender, race and identity at the University of Nevada, Reno. She's a historian of radicalism sexuality and race in the United States, and an interdisciplinary scholar of Queer Studies, American Studies and critical ethnic studies. Her research centers on radical movements of the latter half of the 20th century, especially LGBTQ anti racist and anti imperialist politics. She is the author of two books, Lavender and Red liberation and solidarity in the gay and lesbian left, and

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with Dan Berger remaking radicalism as a grassroots documentary reader of the United States 1973 to 2001 her newest book project examines the history of HIV AIDS activism activism by four and with imprisoned people in the 1980s and 1990s United States, and then fine Oh sorry, I've never liked you say hello. So please welcome Dr. Emily Hobson.

Dr. Emily Hobson

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Hello everyone it's great to be here and I'm really looking forward to our conversation. Thanks so much.

Katherine Fusco

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Okay and now I get to introduce Dr. Elizabeth Miller. So Dr. Elizabeth Miller is an assistant professor of English rhetoric and writing studies and co-director of the writing and speaking in the disciplines program at UNR. She researches and teaches about writing and literacy studies community literacy disability studies and writing again across the curriculum. Her in progress book project Countering Ablest Violence, a disability materiality approach to litter, to literate

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lives learns from life history interviews and community writing groups she facilitated with people who have acquired language disability aphasia after a stroke or brain injury. Her scholarship related to rhetorics of disability ability health and wellness have appeared in college English written communication, the rhetoric of health and medicine, and the community literacy journal, so welcome Dr. Elizabeth Miller.

Dr. Elizabeth Miller

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Thanks so much, honor to be here. Looking forward to the conversation.

Katherine Fusco

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Well I am thrilled to get to be talking with all of you today. I think this is just such a wonderful group of individuals to move us into thinking about building legacies of health and healing. And so by way of helping our audience understand the very different angles that you all take. I wonder if I could ask each of you in turn to say a little bit about the group or groups that your research focuses on, and the particular challenges faced by these groups when it comes to questions of health and healing. And so maybe we'll work backwards from the order we just took so Elizabeth would you consider starting us out.

Dr. Elizabeth Miller

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Yeah absolutely. In terms of, Katherine mentioned a bit of this in terms of my book project in the introduction, I've been doing research over the past several years with folks who’ve acquired language related disability, also known as aphasia. After experiencing stroke or brain injuries.

And, you know, that also was related to facilitating and running some writing and multimodal communications groups, and with in collaboration with a Speech and Hearing Clinic, and also

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students training to become speech pathologists. So from there you know observing these groups, and also doing some life history related interviewing. I really focused on it. I'm a literacy related researcher, so I'm especially interested in, given that a phase affects people's speech, reading, writing, and you know, reception of language. How do they adapt to reading and writing? After this major, major change.

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So, you know something else tied to feature is often a weakness on the right side of the body. So even in terms of typing handwriting, so much about how people process language or even folks talk a lot about looking at a text and finding, you know, densely printed text sort of running together so all of these changes in terms of experiencing reading and writing. But then something else that I can say more about later as we might talk a little bit more about identity is, I'm especially interested in how folks with aphasia are are grappling with how they understand themselves as literate or not, or

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literate in the right ways and a number of my of the interviewees I worked with, used to be teachers one was a retired chemistry professor one was a pilot. So there's folks who have had these rich, you know, career experiences that require reading and writing in certain ways and so I really have together with, with some of these folks explored disability and literacy and sort of like change and literacy in those ways. So to the question just you know One One little additional bit of information here to the question about in sort of health related issues, broadly for for groups I work with aphasia because it affects communication does really affect even

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how folks are accessing, you know, health care, how they're understood as responsible for are competent to communicate with health practitioners and aphasia is really misunderstood in terms of, It affects people's ability to produce and receive language, but it does not affect this is sort of a tag line of the National Association doesn't affect intelligence. And so it doesn't affect the fact that people are you know interested in responsible for their own financial decisions healthcare decisions and often health practitioners in sort of misunderstanding that might talk only to family members and sort of you

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know the sideline or continue to infantilize people with aphasia so that's you know I'm interested definitely in those kinds of access issues as well.

Katherine Fusco

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Great. I'm very excited to see how this conversation is going to come together exciting there might be some really interesting threads to pick up, Emily, could you say a little bit about some of the groups that you're focusing on in your current research and the particular challenges that the individuals that you're working doing your research on might face when it comes to health and healing.

Dr. Emily Hobson

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Yeah, absolutely. So, As Catherine had mentioned my current research is looking is a historical project looking at HIV and AIDS activism by foreign with people in prisons in the 1980s and 1990s United States so these are people who are facing HIV and AIDS. In the first, you know several to 15 years of the epidemic, known as being understood. And prior, for the most part. Prior to the introduction and availability of highly effective antiretroviral treatment or hurt or which is the kind of acronym for the set

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of medicines that begin to come in from 1996 onwards, in which people who are living with HIV still really benefit from and use in order to. At this point you know for many, at least in the United States, able to keep their levels of HIV undetectable. Right, and really have a pretty long and relatively healthy life right. Despite living with HIV. So for the most part people I'm looking at are living at the moment of time when there are very few effective drugs to treat HIV disease, and even those drugs that do exist are often really toxic on the body right so they may

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kind of assist in fighting some expressions of HIV disease but overall negatively affect people's health. Moreover, the people I'm, you know, working, doing research on include, you know, significant numbers of people in prison who, in general, do not have good if any real access to consistent health care, right. In addition to often being denied medications, especially if they're moved within a prison to different units in the prison or losing track of medical care, you move from one person to one another.

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Also, simply people in prison do not get access to the most cutting edge or the highest quality health care. So, people living with HIV and AIDS in prisons in the 80s and 90s in particular, really have very serious threats, have very severe illness and and you know continues to be quite difficult to access HIV medications, from the inside, although it is, you know, there's greater access. And then in addition to people in prisons themselves. I also really am focusing on Coalition's built with outside activists, some of whom also were living with HIV and AIDS but with someone with greater access to care.

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And for those folks. I think the relatively better access to care, even though is very contested, very difficult, you know, drug trials slow, like, and, you know, the drugs simply not necessarily

being so great. To begin with, their contrast was really important to the kind of coalition building people were able to do. So one of the things I've noticed in my research is that one of the huge challenges faced by people in prisons was simply information about what drugs were available and so therefore what they should advocate for for themselves and collectively as well

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as what kinds of alternative treatments people were using on the outside in terms of things like nutrition. And, you know, stress reduction and other kinds of practices, HIV disease as many of you probably know you know one. When you have HIV, the course of illness, you know, one can live with HIV for a long time without it progressing to AIDS, but what produces that that progression to AIDS has a lot to do with your overall access to health care your overall health overall

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stress overall access to nutrition secure housing and things like that. So you can imagine all the different ways that being incarcerated, of course will accelerate HIV disease to AIDS, and that, you know, figuring out forms of self advocacy and collective community building also can really go a long way to helping people develop forms of maintaining their health over the long term. So, those are some of the issues that come up in the research and I think there are a lot of lessons for us now. For sure.

Katherine Fusco

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And then I'm Melanie if you wouldn't mind I know you work with lots of different groups and have a long list of publications and different groups that you've worked on who face challenges but I wonder if you could pick a group or two that you're particularly interested in what you think might be relevant for thinking about, you know, a group that you might describe and the challenges facing one of your risk groups.

Dr. Melanie Duckworth

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I actually have one primary focus in terms of my research, and it's looking at the trajectory experienced by people who have been involved in very serious motor vehicle collisions. So it's a context for unintentional injury. And it's a context where we can all reside. So it is interesting in that anybody can have a collision. And so what we deal with his identity defined broadly and life circumstances and experiences defined broadly,

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but in the context of that particular unintentional injury context, what we have is a cascade of effects occurring. So typically if it's a serious collision, the person will experience physical impacts that are associated with impairments and function, and sometimes disability. So difference between those two terms impairment is a change to a bodily part of body part, or an

organ system in a potential change to the function of that body part, an organ system. A disability has to do with the impact of that impairment, on the person's ability to engage in what we would consider normal activities of life. And so what we find is that a person will experience a physical injury that will oftentimes impact their ability to work.

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And then that impacts their ability to sustain whatever kind of financial well being, they had prior to the collision. That usually causes stress that has a psychological component to it. If you have physical pain impairment, and you have psychological distress, it is very likely that you are not able to be your best self in the context of your family other loved ones friends, and you are very likely to not want to engage in anything that

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would have normally brought you joy and some kind of pleasure so it's just this cascade where the collision becomes a Nexus in terms of having physical injury meet up with psychological injury and in the collision context that psychological injury can be of the most severe types so collisions can oftentimes be traumatizing so there can be loss of a body part there can be death, there can be, you know, a belief that death is imminent so all those things would qualify collisions as criterion, a events

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and sufficient to cause trauma. So we look at that and we recognize that the person who is trying to restore their life function is going to have to engage with systems, and in the collision context, not only do they have to engage with medical systems, but they have to engage frequently and intelligently with the legal system. So, in terms of compensation compensation in the injury context is often about loss of work productivity, so it can be you haven't lost your job, it can be you now only being able to work part time or it could be you not ever having lived up to your potential.

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So you were just about to graduate college, and you have this collision, and you would have had x degree well what money would you have made with that degree, and that's what they calculate. So if you think about having your health managed by virtue of you making a sufficient legal case to get compensation, you can see how challenging this is. So in terms of identity for that population there are a number of factors that are relevant. So if we look just at physical injury, gender and age are very relevant so we know that collisions that involve older adults are more likely to result in them dying in fatalities.

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We know that injuries that occur to young persons particularly males are going to be very serious and more likely to result in some kind of permanent disability. We know that women are going to have injuries that are not as documentable, and so not regarded as a serious as a fracture would be so we will have soft tissue injuries, the whole population will experience, not the whole population but some people experience

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brain injury and that could be traumatic or mild, those things are harder to diagnose. So there are a lot of variables that pertain to identity that are relevant to how an injury is assessed and treated and compensated. So I'll stop there.

Katherine Fusco

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Well that yeah that's a great lead into kind of my next question and I do want to remind folks that if you would like to ask our panelists questions about any of their perspectives on health healing wellness injury and go ahead and put back in theQ&A. But one thing that several of you have touched on is the way in which acquiring a traumatic injury or a disability or a new disease right, all of you are in some ways working on people who. This is a life change right, this is something that the individuals we're not experiencing before and now they have a new illness, they have a new disability they have a new traumatic injury.

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And so I wonder about, you know, if you could talk a little bit about some of the most striking ways. This seems to be affecting individuals self identities and also this question of how individuals relate to society does it you know, how does this change the way an individual feels about their role in society. And so actually, Melanie since you were just talking a little bit about this it seems natural to ask you to kind of continue on this.

Dr. Melanie Duckworth

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In terms of the injury context. We have a sense of ourselves as whole how, in whatever form we take, we have this history of this as us. And so when somebody has an injury that requires the removal of a limb or now requires rods to be placed in three out of the four limbs and the other limbs amputated when it is dead extreme. There's a loss of sense of continuity of self, that is a real challenge. So it's not only about going out into the larger world, it is simply sometimes just confronting what

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is now your new self. So that can be challenging. It is also the case that for many of us work is our definition of self for good or for bed. We define ourselves by what we do, and suddenly we have somebody who can no longer claim that occupational label. So who are we, if we are not doing what we've done for 20 years who are we so there are real challenges around maintaining a sense of self in maintaining a sense of purpose in in this new lived experience of the body and the ability

Katherine Fusco

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Elizabeth I might ask you to pick it up so it seems like a natural kind of connection to your research.

Dr. Elisabeth Miller

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Yeah, absolutely. I think so much resonates there with it. So, you know, a phase of people. In fact, there's a good, good amount of Communicative Disorders research that calls aphasia identity theft. Because, communication is so central in forming our identities you know we're growing our identities between each other in communication. So, as a daughter with a mother or, you know, within a family at work.

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So, communication is central to forming our roles and how we understand ourselves and so exactly as you were saying Melanie about this new a new sense of self in creating a new sense of self is something that is, is really central for a phase of people who, who I was talking to and so that was actually part of the rationale for for writing groups for composing groups that were kind of scrapbook like, but which we actually called in these republican Mandy's context.

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In collaboration with the spirit Speech and Hearing Clinic, that I was working with their life books people were creating life books, where do they might put in you know old ticket stubs or old pictures or drawings or, you know some language but just sort of the retelling and then in groups, community groups with other folks who are adapting their new sense of self as as a person with aphasia.

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So, that sense of sort of restoring your life was really central to kind of the broad effort of these community, community groups, community writing and communication groups I was involved with. And I'll also say, you know, this identity for me again invested in literacy research. I've really been focused on, folks, the change in sense of their, their literate identity. So, you know, especially some, some people in in my interview group who used to be teachers who might even not others might not even notice they have aphasia

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they sort of might pass as not having aphasia they still continue to read and write, social media, reading novels, you know, writing emails lots of things. But, you know, many of them say, I am not literate anymore. You know, some of them as a result would stop reading and writing because their handwriting would really different, or because it took them so long it took them longer and they notice the difference

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So some of my research really looks then at these norms around being literacy in the right ways. And so, you know, parts of my book project are kind of getting at. Yeah, what is this sort of normal? I call it a Normal template so sort of understanding a normal person is literate in the right or normal ways. And then how that really pushes back on people and their identities in all kinds of ways that, again, keep them from trying out new things taking on an audio book because for them that's not reading or they're not they're not, sort of, you know, retaining that you know correct literate identity.

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So those are some of the things that I think link up especially with your research Melanie.

Katherine Fusco

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Yeah and I actually might stick with YouTube for just a second kind of follow this thread in either Melanie or Elizabeth. Do the folks that you're working with have a changed sense. So these are people who are acquiring a disability or who are acquiring and impairment does that change their perspective on the broader society so you both talked a little bit about the kind of identities of these people and how it changes their self conception, does it change their sense of what the broader world looks like or you know whether that's in terms of the way the world works or doesn't work with people who have disabilities or

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in terms of, you know, does the world seem like a different kind of scary place or I'm just curious about how that might change for people as well.

Dr. Melanie Duckworth

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Would you like to go?

Katherine Fusco

Sure, go ahead. I guess this is the real moderating Yes.

Dr. Melanie Duckworth

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That's such an interesting question, and it relates perfectly to what Elizabeth described as this movement from an individual normal in that individual normal might have surpassed what we would all agree to as normal normal, but for them that detriment and function is such that they put themselves below normal. And so what we find in my context is that people can sometimes be so self limiting, because they are totally concerned about doing things in the exact way that they didn't before, and having

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all of the capacities that they had before. Rather than saying, I can do this and I can do it to a completely normal and probably still a little bit beyond normal in a positive way degree, but that's no longer acceptable so they have a different sense of who they are and what their potential is in the world and how they can move out into the world so Elizabeth talked about people stopping reading, we will have people not do a job not because they can't do it to the requirements of the job but because

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they can't do it as easily or as quickly, or with the level of perceived competence and comfort that they did it initially and so that can be a self limiting process, but then what they find in the world is that we have biases, we have biases that would say ability is the only place to land on a continuum of diverse abilities. They're like whatever normative ability is that's what we consider to be the optimal moment.

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And the truth is we need to have a, an awakening around what is very positive about having abilities that differ from what we would consider normal or normative, so it's both ways they experience change internal change and change in terms of how they're perceived

Katherine Fusco

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Elizabeth did you want to respond as well and I've got a question for Emily after that.

Dr. Elisabeth Miller

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Absolutely, I can just briefly say, Melanie you and I should talk more I feel like I would love to. Even so, many intersections and, and I think yeah for me again as someone really invested in literacy and disability. I mean, the, the intersection their experience of disability for people often you know just going straight into illiteracy, that there's no real room in literacy for a lot of folks sort of self definition of literate identity or what literacy should look like, you know, either literate, or I'm illiterate and and that's really dependent on even you know the ways their bodies are working

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how, how, you know, quickly or slowly there, you know processing summit which, again, you know, makes a lot of sense. But folks are also you know they're they're doing the work of reading and writing or they're there, you know doing often really complex communicative tasks, but then still see themselves as not doing it right. And I guess I will say there are all kinds of interesting moments that you know I've witnessed in groups with folks and also you know learned about self advocacy.

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So even just you know one participant said you know I could hide. But I choose to go out to a coffee shop and talk to people and you know and sort of bring their, their style of communication which, you know, she said might be slower but she said, I'm a Facebook and I have a right to live and and be a part of communication and so that's been interesting to to see people, you know, navigate that okay you know how do I see myself differently but how do I see myself, integrating or even challenging society's norms around communication.

Katherine Fusco

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I do want to shift a little bit I don't want to lose track of Emily's research, but it seems like there might be, I mean I think we have a lot of stigma around disabilities of the kind that Melanie and Elizabeth they're describing but there's a particular stigma, especially in the 1980s and 1990s around HIV, and so Emily I wonder if I could go back to the the original question about how acquiring HIV affected people's self identity and also, you know, in the kind of unfriendly world of the 1980s and 1990s, where they perceive their relationship to a broader society.

Dr. Emily Hobson

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Yes, absolutely. So there. I will say that I think that you know of course, there's a lot that affects the sort of meanings of stigma for HIV and AIDS depending on how people realize that they were either ill or living with HIV right so there's a difference between suddenly becoming quite ill. Right, and realizing that that is Acquired Immune Deficiency Syndrome right which is this complex of illnesses. There's a difference between that and being otherwise feeling like you're relatively healthy but learning that you have HIV, right.

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Both of those have stigmatizing effects, but you know I think the sort of sudden illness also has the sort of compounded effect of the illness itself, the sort of isolation that often comes with severe illness. So, some of the effects of that stigmatization sort of very with kind of where people were at. And for people living in prisons, sort of general lack of access to health care, especially early on and to have more in the 1980s, as there was less testing or if they were in prisons where there wasn't mandatory testing that might have, you know, uncovered

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HIV at a sort of earlier stage. The often sort of how they came to understand that they're living with HIV and AIDS was this kind of very dramatic scale of illness. The other thing that I think is really significant right of course is there's, you know, HIV and AIDS remains stigmatized, as this gay thing, right, and in fact, the early name for the disease was gay related immune deficiency, right for the first couple years before the name change.

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So, you know that stigma, like has remained long lasting and of course is partly, You know part compounds the stigmatization of any disease. And also kind of created a distance right was sort of homophobia and also more related to that transphobia were kind of forms of distancing that many different people, certainly, both inside and outside of prison have long used to sort of try to separate themselves from a sense of risk to HIV or kind of awareness about HIV and AIDS as being things that affected them.

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I think another thing to kind of consider is that being imprisoned isn't self stigmatizing. Right. And itself affects people's identities right so to kind of enter into the institution and have to kind of adjust to the norms and the, the isolation and the alienation and the trauma itself, of being institutionalized itself effects of people's identities. So, certainly for people in prisons who, you know, are going in and then become ill or learned that they're living with HIV there is just this compounded scales of multiple kinds of stigma.

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The thing that I really have been compelled by in my research is the power with which people responded to that, with, you know, forms of self self advocacy and collective work which I think we'll get to in a little bit. But just to kind of set some of the context project you may be hearing a little bit of dogs in the background, even though doors, you're The one thing to sort of set some of the context for some of my work that is that, I think there is a common misconception when I talk to people about my research that I must be talking about men's prisons and also about transmission inside prisons.

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But in fact, the very large proportion of people living with HIV and AIDS, who are incarcerated both in the past and the present became infected with HIV, prior to their incarceration. So it's really kind of the circumstances that made them vulnerable to HIV or interwoven with the circumstances that made them vulnerable to criminalization or incarceration. And that also is kind of reflected in the ways that the rates of people in women's prisons living with HIV and AIDS are greater than the rates of people living in men's prisons.

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So numerically, it's more people with HIV in men's prisons because it's just more people in men's prisons in general, but that proportion is sort of higher and that also kind of affected those differences of gender affected. Some of the ways people were able to respond.

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In that, you know, I think, kind of some of the ways of relating to each other. That helped to break down some of the stigma surrounding HIV and AIDS, in some ways, you know we're facilitated by the shared experience of being women or, or, you know, being classified as women and living in that context.

Katherine Fusco

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That's so interesting, I would have made I think the exact same assumption that you say people bring to your research so thank you for that I do want to remind folks that if they have questions do you feel free to put them in the Q&A, but I would to invite Emily for you to continue talking a little bit about advocacy because I think, you know, I want to shift towards the building legacies of health and healing pie right we've spent some of this evening talking about sort of the challenges that folks face the challenges there are structural the challenges that needy psychological as well as physical.

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But I would love to hear stories about individuals coming to advocate for their well being. When they exist inside of structures that are maybe not doing enough. And so I would love for you to share either individual stories or collective strategies that you've encountered with your research and so I'll let you start Emily since this is very close to your work.

Dr. Emily Hobson

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Yeah, great. So the focus of my work is not so much on the sort of circumstances or like the epidemiology of HIV and AIDS in prisons but really rather on how people responded with forms of collective action. Inside prisons the thing that's really noticeable is a network of peer education projects that incarcerated people developed in collaboration with, with support from activists outside who shared resources, you know, on HIV education and prevention tools curriculum tools, things like that.

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But it was people inside prisons themselves who really developed a peer education model that they, you know, then pushed to to have accepted by presence to be allowed to, you know, provide curriculum to each other and to create peer counseling programs. So, the first two of these were created in New York state prisons in 1986-87. The first one was at a men's prison called Auburn. And then the second one. Immediately after that and that really developed and became more flourishing was at a women's prison called Bedford Hills, and that project became called aids counseling it and education or ace.

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In general, the peer education projects inside women's prisons sort of flourished more and we're less repressed by prisons. There's kind of a greater repression of organizing inside men's prisons. In general, and all of these pair education projects were multiracial very consciously So, which, you know, was perceived as a political threat. But as somewhat less of a threat in the context of women's prisons. I also think that the forms of kind of peer counseling relating to each other building community emotional kind of sharing of experiences, was sort of more accepted among people in women's

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for people in women's prisons. It kind of more accepted form of behavior, you know, fits into norms of like how women are supposed to relate to each other versus how to relate to each other and particularly in the context of a prison. So it really flourished. And, you know, it had some sort of hiccups along the way but it wound up involving hundreds of people inside the present at various scales, you know, some sort of a basic level of going through a one in one kind of training. Some also prison guards and administrators, like kind of went through education programs that the people who ran are put together.

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And then also some more involved like leadership teams and one on one counseling projects, and the curriculum. The curriculum done got shared with you know some other prison projects, including in the federal system. And in, also in prisons in California, in Illinois and a few other places. And, you know, generally, it was kind of like movement through a kind of, here's what HIV and AIDS are, here's how they operate in the body, some of the biomedical information to then address issues of stigma stereotypes around HIV and AIDS stereotypes around sexuality.

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A lot of attention to how to negotiate safer sex and HIV prevention on the outside, after release. And like relating to families talking to family members talking to children about living with HIV and AIDS and so forth, legal issues also, you know, concern around losing legal right to parents, right, if one is living with HIV or AIDS. So, there was this kind of host of issues addressed and then usually the curriculum also would wrap up with a kind of larger discussion of the politics of the HIV AIDS epidemic, right, like, how is it that people were advocating for more research for

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more HIV and AIDS care, both inside prisons and outside. How did issues of race and class and gender shaped the dynamic and shape who's vulnerable as well as course, issues of homophobia. So it really was a kind of very flourishing set of projects. The other main thing that I've looked at are the coalition's that developed as I mentioned between incarcerated people and people on the outside, but I really think that the peer education projects really capture my own kind of excitement as some of those innovative work that shows up in this history.

Katherine Fusco

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Yeah, that's really great and I think I'm yeah I'm very excited to hear also Elizabeth and Melanie's response to that question because I think this idea of kind of like self advocacy and also maybe taking on this new kind of identity with a new group right like that, who your peers are can become different over time. And so, Elizabeth I wonder if you could. I know you've done this work on these circles if you could talk a little bit about interesting ways you've seen people either advocating for themselves or for this new group that they find themselves among.

Dr. Elisabeth Miller

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Yeah. Yeah. Um, I think, you know, one of the things that I would note right away is I actually ended up recruiting folks for some of these, these public humanities kinds of projects I was involved with out of an aphasia self help group. And so there was already a really vibrant sort of self help network in the community I was in and it was, it was really powerful in terms of weekly meetings with people who've recently acquired aphasia meeting others who had been living with aphasia for quite some time. And so I think that actually ended up transitioning really nicely into some of these storytelling groups where we sort of that community then extended into my experience with these writing communication groups.

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So, I guess I mean the other thing I would say is, you know, so many. I think advocacy around aphasia. I mentioned you know one interviewee saying you know I'm going into the community and just, you know, communicating in the way I communicate so sort of these daily advocacy moves and also you know another another interviewee who said, you know, when I first acquired aphasia. I couldn't read any websites that were about aphasia because they had dense text that was not, you know, sort of, aphasia friendly, it was not spaced in ways you could quickly access it didn't have an

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option to have anything read aloud it, and you know she said, Hey, I have a partner who helped me. But what if I didn't, and you know, so what if I didn't have sort of a care network. So she worked on sort of an aphasia friendly website going forward so there were some of these really for community members so there's some of those really powerful moments but I think to, you know, that interview he was noting something that really showed

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up in my research which is, folks, there's a certain level of privilege to hear to even to get to a point of advocacy right so, you know, who has a good care network already, who lives near a university that has public resources that, you know, programming beyond sort of drill based therapy, like the group's I was involved with. So, I think. And I mean, even though, stroke, brain injury that is particularly stroke. That causes aphasia disproportionately affects people of color.

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It's also the case that, you know, very few people of color were accessing for instance the Speech and Hearing Clinic I was involved with. And so, you know, disproportionately also folks are in institutions, or care institutions or have just, you know fewer. I know we're talking about advocacy here and I want to focus on that part but I do want to say, you know, the resources around, enabling advocacy to flourish, I think, really kind of showed up over and over again even though I did see these really powerful moments of, you know, in a group, sharing experience and coalition in that way or kind of individual advocacy.

Katherine Fusco

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And I want to actually throw a different question to you, Melanie which is about ableism so I'm Professor D on asking if there are ways in which challenging ableism could help people who are not disabled or benefit the broader community right so, and I think you. You all look that all of you are working on disability but, you know, the acquired disability is one kind of thing born disability as the different kind of thing but I think there's this question of, you know, what would it do for society in general if we kind of challenge some of these assumptions are able to cultures and so I'll let you start Melanie,

Dr. Melanie Duckworth

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Zoom world. I knew it would happen. I mentioned it. I think there are two ways to go at that question. One is with an emphasis on inclusive city in inclusive city of, people who are considered to sit at the center of normal ability and expanding that out to capture all types of diverse abilities will mean that we have so many more creative. You know ingenious inputs into any question that we're trying to answer so you know it is so interesting to think that one's perspective is the perspective.

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And so you know it's it's it's the issue of, you know, I'm trying to determine, you know that you have an elephant in front of you by touching different parts of the elephant and the whole thing is we are going to have so much of a greater appreciation for any moment that we're in if we appreciate that our perspective is not the only perspective. So that's one way to get at this. The other thing is there's rarely. I don't want to say an accommodation but there's rarely a technological advance that would serve somebody with a disability, that doesn't serve someone who is considered to be at the center in terms of normal ability.

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So if it's the case that we are watching a film and then there's captioning. You know that can be an advantage to somebody who would be perceived as completely normal in terms of their cognitive function, but they just have a tendency towards written words versus hearing things, there's just this slight preference for that. So in so many cases, when we are attempting to have equitable solutions they end up, managing challenges that we didn't even identify in our able moment.

Katherine Fusco

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Emily I may ask you the same question.

Dr. Emily Hobson

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This is the question from Dr do. Yes, okay. So, yeah, unable ism. Yeah, I mean I think of you know my own work doesn't center on disability or disability activism but as a historian of social movements I've certainly learned a lot from learning more about the disability rights movement and Disability Justice Movement and I end up teaching on concepts of Disability Justice in for example my classes on feminist theory at the undergraduate level, and the framework of Disability Justice has really given me a really rich way to think about illness, and health more broadly,

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and the ways that it intersects with the sort of perceptions of health and illness intersect with questions of gender of race, class, of productivity, of age, many different kinds of factors and I would say, you know, for one at a very concrete level. You know, we think I think we tend to think of disability as this kind of status that is fixed, but it is a status that is actually often very shifting, you know, we can become temporarily disabled with an injury that we eventually he'll from, we can

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disabled as we age, right. And so you know as Melanie was saying like many of the kind of forms of access that you know are kind of geared towards things that are thought of as permanent disabilities or permanent and pyramids, really can help us you know in particular moments right like curb cuts help if you're pushing a stroller, you know, or if you're older and you're using a wheeled cart for your groceries. Right. And I use live transcription or captions, all the time.

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Simply because you know I find it a little easier to absorb or if I'm watching a British detective show and I cannot understand the accents, you know. So I think there are many kinds of concrete things like that. I also really think that, you know, understanding able ism as a problem, as a is a really helpful critical tool for me to think about the ways that that norms around like what it looks like to have a healthy body are interrelated with structures of racism structures of sexism hetero sexism assumptions about size things like things like that right and thinking about the history for example of eugencists thought and the ways that eugencists

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thought, often you know marks off people with disabilities as not worthy of support or not even worthy of life for me has been really profound in understanding the ways that the way that white supremacy and other kind of aspects of eugenicist thought are interrelated. And then, you know, I also think that like Disability Justice also advocates for a stronger social safety net. And for healthcare access, right, and for understanding, chronic illness as on the spectrum of disability and that's something that we certainly

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can all benefit from

Katherine Fusco

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and Elizabeth I might ask you the last question but in a slightly different form so I wonder what you think we as a society can stand to learn from the kind of groups that you're studying. So, you know. Are there new ways that we should be thinking about ability trauma or illness or their new ways that we should be thinking about? Are there new policies we should be developing? What could we learn as a society from thinking about the folks that you've been working with?

Elisabeth Miller

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Yeah, I hate to be the last word. But I will say, you know, I think that this model of a republic humanity storytelling group that I was involved in really was pushing back on some of it was it was located at a Speech and Hearing Clinic, but it was very different than a lot of the other programming or more traditional therapy available at the clinic for amazing people. And so a lot of the other therapy was very, you know, sort of drill based and sort of, you know, trying to very much, you know, regain

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competency in terms of speech and and you know that has a lot of place in in this whole sort of healing journey but I think more broadly thinking about healing living with a disability aphasia is is chronic it, it changes people's bodies and experiences with language in the long run and so you know groups like this that can focus on storytelling, or sharing experience in ways that really translate, like I said this group for instance was very tied to a self help group and so conversations between groups

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of friends would extend would build off of these kinds of sharing of stories and experience. So me this sort of a broader push toward health through participating in life, and sort of what our goals are for in health I mean are we getting back to how we were. I know we've all talked about this in certain ways. Tonight, or, you know, are we talking about participating in the world in different ways and pushing back on norms of communication or bodies. And so for me that's had lots of implications in in other ways even in the ways I do research, I, I learned a lot from people with aphasia who I was interviewing, I used illustrated consent forms based on a lot of feedback from folks and how they best

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communicated. I did a lot of drawing and writing in interviews from a multimodal interviewing kind of strategy. So, you know, it sort of more broadly examines how we research. And obviously, teaching how we understand, you know, good writing, good students. So for me, those things are all kind of interconnected from, from my project.

Katherine Fusco

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Well I also love that as a final question he said you didn't necessarily want the last word but I think this idea that does run through all of the work that you're doing is about people kind of telling their own stories or figuring out how to tell their own stories, and how to make connections, and I think, you know, as we are all living through this kind of mass trauma right now right and you know facing different health effects of the moment I think it is so important and, you know, I really appreciate you all being here to make this connection tonight and I appreciate those of you who are in the audience this evening for you know coming out and have a little, a little bit of connection, a little bit of seeing faces a little bit of thinking together. I want to say thank you to the panelists, thank you to everybody who helped put this event together and who’s here tonight. I do hope you all will take our survey at the end but also take good care of yourselves out there. Thank you panelists.