3 - C: Models of Resistance: Disability Justice and Other Activist Interventions

Given the biopolitical nature of life with connective tissue variations, people with both acquired and genetic variations have been active in countering the reductive model of science and medicine and engaged in disability activism. In recent years, social media has been a particularly useful tool as many people with connective tissue variations have mobility limitations that prevent them from organizing in physical space. That said, for many years people have used in-person support groups to navigate local medical systems. It is important to remember that recent social media activism didn't come from nowhere; it grew from past models of activism. And, even today, there can be real value to local networks of support and care.

Hyp+Access is an example of a group that is working both locally and actively on social media. The organization was founded by L.Tuthall and Audre Wirtanen with the mission of community based education and care built on the Disability Justice model (more below). The group uses social media for education and outreach, but offers in-person training and care in New York City. As of October 2026, Hyp+Access is in the process of creating a care program for people with hypermobility related variations of connective tissue. This project works to directly counter the reductive model of medicine by bringing together medical and non-medical specialties into one space to improve care. However, this project is more than just a "specialty" clinic. It envisions a model that centers access, care, and consent–elements that are often missing from the mainstream, reductive model of medicine. Indeed, Hyp+Access' focus on people with hypermobility, broadly speaking, allows the group to resist some of the problems of categorization described in section 2-b. Hyp+Access' scope is grounded in an expansive, and thus inclusive, framework rather than one that is reductive, and thus exclusive.

Principles of Disability Justice

Some people with variations of connective tissue don't understand themselves through the framework of disability for a few reasons. First of all, many people, particularly those with acquired/autoimmune connective tissue disease, use the framework of chronic illness to understand their lives. Chronic illness describes the state of being sick, feeling poorly, or suffering over an extended period of time. Not all disabled people experience being sick or feeling bad as a result of their disability. So, in some ways the distinction between "chronic illness" and "disability"

is an important one. However, the framework of disability has some important elements that can be useful for people who understand themselves as chronically ill. The social model of disability frames disability as something that is produced by societal structures that make the world inaccessible to people with impairments. Said another way, disability is not an individual trait or deficit, but the result of discrimination. While disability and chronic illness may be different, accessibility is an important concept for both groups of people. And, while it is a bit more complex to understand chronic illness as a "social construct" the experience of being sick is very much shaped by social structures as we have discussed. For these reasons many people with variations of connective tissue are beginning to gravitate to disability as an important framework for making sense of their lives.

Disability Justice is an activist paradigm developed by Sins Invalid, a collective of disabled artists/activists. The framework grounds itself in ten principles (see box). Study these principles and then use the questions in section D, below, to reflect on how they might be used to counter the reductive model of medicine and improve the wellbeing of people with variations of connective tissue.

Ten Principles

1. *INTERSECTIONALITY "We do not live single issue lives" –Audre Lorde. Ableism, coupled with white supremacy, supported by capitalism, underscored by heteropatriarchy, has rendered the vast majority*
   of the world "invalid."
2. *LEADERSHIP OF THOSE MOST IMPACTED "We are led by those who most know these systems." –Aurora Levins Morales*
3. *ANTI-CAPITALIST POLITIC In an economy that sees land and humans as components of profit, we are anti-capitalist by the nature of having non-conforming body/minds.*
4. *COMMITMENT TO CROSS-MOVEMENT ORGANIZING Shifting how social justice movements understand disability and contextualize ableism, disability justice lends itself to politics of alliance.*
5. *RECOGNIZING WHOLENESS People have inherent worth outside of commodity relations and capitalist notions of productivity. Each person is full of history and life experience.*
6. *SUSTAINABILITY We pace ourselves, individually and collectively, to be sustained long term. Our embodied experiences guide us toward ongoing justice and liberation.*
7. *COMMITMENT TO CROSS-DISABILITY SOLIDARITY We honor the insights and participation of all of our community members, knowing that isolation undermines collective liberation.*
8. *INTERDEPENDENCE We meet each others' needs as we build toward liberation, knowing that state solutions inevitably extend into further control over lives.*
9. *COLLECTIVE ACCESS As brown, black and queer-bodied disabled people we bring flexibility and creative nuance that go beyond able-bodied/minded normativity, to be in community with each other.*
10. *COLLECTIVE LIBERATION No body or mind can be left behind – only moving together can we accomplish the revolution we require.*

Disability Justice is a powerful paradigm because it advances big ideas in a way that is accessible. We can all help create Disability Justice, whether we are disabled, chronically ill, or not. The best way to start is to begin truly listening to disabled and chronically ill folks in our communities and around the world. If you have a disabled or chronically ill friend or loved one, you may be wondering how you can help. Disability Justice gives us a framework working together in solidarity.

Rheumatoid Arthritis advocate, Eileen Davidson, has some concrete suggestions of how to support a chronically ill or disabled friend. Disability Justice begins with the care we show one another in our communities. But it doesn't end there. Disability Justice requires us to advocate for changes locally and globally that will address the biopolitical connections discussed above, too.

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