

EQUITY, INCLUSION, & DISABILITY
An educational resource series for the UMass Amherst community

“When we speak of disability we are celebrating the brilliance and vitality of a vast community of peoples with non-normative bodies and minds, whether a disability is visible or not.

This includes, though [is] not limited to, folks who identify as disabled, chronically ill, Deaf, mad, neurodivergent, and more.”

Showing Up For Racial Justice
Disability Justice Caucus

DEFINING DISABILITY
What is disability? And who “counts” as disabled?

Defining disability is more complex than it might seem! When asked to imagine a person with a disability, many people are likely to picture someone with a visibly apparent physical or mobility impairment – consider that the most widely recognizable symbol of disability depicts a wheelchair user. However, physically disabled individuals are only one facet of the highly diverse and dynamic social identity group united through the lived experience of disability. Numerous definitions of disability – medical, legal, political, educational – demonstrate the complexity and nuance of describing an experience that is malleable, contextual, and relational. In order to broadly explore the topic of disability as it relates to the UMass community, this toolkit series will intentionally embrace an expansive definition of disability that includes visible and invisible disability, as well as conditions that are self-identified, medically diagnosed, and/or externally perceived as a disability by others.

Historically, disability was commonly understood within the context of religious and medical models. The oldest of these, the moral model, associated disability with sin or wrongdoing, and posited that disability was the result of moral weakness. Along with the advent of modern Western medicine, disability was still understood primarily as a deficit or defect, but one that could now be “fixed” through intervention by expert medical professionals in a medical rehabilitation model. Both of these models contextualized disability as an individual problem that placed disabled people on the margins of society, emphasized their differences, and assumed that all disabled people should want to be as close to “normal” (i.e. non-disabled) as possible. The burden of inclusion fell solely on disabled people, instead of on a dominant culture that failed to account for their differences and attune to their needs.

Largely as a result of advocacy from the disability rights movement, the prevailing contemporary model has shifted to a social model of disability which posits that the deficits lie not with the individual, but with a society that does not value their inherent worth, account for their unique needs, or seek paths to full inclusion for all. As described by disability activist Deborah Kaplan, this model “recognizes social discrimination as the most significant problem experienced by persons with disabilities, and as the cause of many of the problems that are regarded as intrinsic to the disability under the other models.” In other words, disability itself is not the issue – environmental accessibility, cultural stigmas, and social constructs about disabled people’s experiences, abilities, and intrinsic value are. While people with disabilities may still choose to pursue various medical treatments and interventions, the social model of disability intentionally centers the agency of individuals making decisions about their own lives and bodies.

Contemporary disability justice advocates further encourage us to see disability as a dynamic spectrum, as opposed to a static, binary identity. The idea of being “temporarily abled” acknowledges that most people will experience conditions of disability at some point in their lives due to illness, injury, age, and other variable factors. There is also a deepening recognition of the ways in which invisible disabilities, especially those related to neurodivergence and mental health, deserve intentional consideration in conversations about equity and inclusion.

ABOUT THIS RESOURCE
This series was developed by the Office of Equity & Inclusion in collaboration with campus partners to provide the UMass Amherst community with foundational knowledge and language regarding disability as a social identity.

It is intended to provide access points for learning, reflection, and engagement for ALL community members, including people with disabilities, and those who seek to be in active allyship.

As you explore this toolkit, click on any image or underlined text for links to additional resources!

This toolkit series invites the UMass community to...

- Consider what we know (or think we know!) about disability,
- Explore the impact of socialization and dominant cultural narratives on our understanding of disability,
- Practice applying disability justice as a LENS that will repeatedly ask us:
  - What does it mean to think and act in anti-ableist ways?
  - How does disability interact with other aspects of social identity, particularly for community members who experience marginalization around multiple sites of identity?
  - How can we treat disability justice as a way of perceiving the world, not just an inclusivity “checklist item”?
### DISABILITY RIGHTS HISTORY

What are some key moments in the history of the modern United States disability justice movement?

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td><strong>mid-1950s</strong></td>
<td>An era of deinstitutionalization saw widespread closure of state mental hospitals and a shift towards community-based health services and rehabilitation</td>
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<td>1954</td>
<td>Brown v the Board of Education Supreme Court decision ruled that race-based public school segregation was unconstitutional, providing a foundation that would later support the argument for desegregating education for children with disabilities</td>
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<td>1954</td>
<td>The Independent Living Movement begins with the first Center for Independent Living, a service agency run by and for disabled people, opening in CA in 1972</td>
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<td>1972</td>
<td>The last remaining “Ugly Laws” -- statutes that prohibited the public appearance of people with visible disabilities -- are repealed in Chicago</td>
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<td>1974</td>
<td>The 504 Sit-In sees over 120 disabled demonstrators occupy the Department of Health, Education, and Welfare (HEW) building in San Francisco for 25 days advocating for enforcement of disability rights legislation. The sit-in draws cross-movement support from the Butterfly Brigade, the Black Panthers, unions, Civil Rights groups, the Chicano group Mission Rebels, religious leaders, and local lawmakers</td>
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<td>1977</td>
<td>During the “Capitol Crawl”, disabled protestors abandoned their mobility aids and climbed up steps at the National Mall to raise awareness of the struggles that people in the disability communities face, spurring Congress to pass the Americans with Disabilities Act</td>
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<td>1990</td>
<td>The Disability Justice Collective, led by disabled, Queer activists of color, ushers in a “second wave” of the disability rights movement that explicitly examines disability in relation to other forms of systemic oppression and calls for solidarity with other social justice and civil rights movements</td>
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<td>1999</td>
<td>The Olmstead v. L.C. Supreme Court case rules that unjustified segregation of people with intellectual disabilities is a form of unlawful discrimination under the ADA</td>
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Note: This timeline draws on content from the text Teaching for Diversity and Social Justice (4th ed), as well as input from Hillary Montague-Asp and Davey Shlasko.
CONTEMPORARY CONCERNS IN THE DISABILITY JUSTICE MOVEMENT

COVID-19 PANDEMIC

Beginning in 2020, the COVID-19 global pandemic greatly impacted the disabled community and approaches to disability justice work in many ways. For instance, it has led to increased visibility of the disabled community and recognition of the disproportionate impact on marginalized groups, including people who are immunocompromised, as well as communities of color. The pandemic has also urged people to think about accessibility differently, with many schools, employers, and other organizations offering greater flexibility around remote participation, and more widespread adoption of adaptive/assistive technology that benefits folks with diverse abilities and accommodation needs.

Reflection: Although the Covid-19 pandemic is still ongoing, many institutions/organizations have expressed a desire to return to pre-pandemic norms and procedures. You may have heard the phrase “going back to normal” being used in various spaces, but what implications might this return to pre-pandemic norms have for accessibility and disability justice?

Read this quote from activist and writer Sonya Renee Taylor and consider the questions that follow:

“We will not go back to normal. Normal never was. Our pre-corona existence was not normal other than we normalized greed, inequity, exhaustion, depletion, extraction, disconnection, confusion, rage, hoarding, hate and lack. We should not long to return my friends. We are being given the opportunity to stitch a new garment. One that fits all of humanity and nature.”

- Who benefits from going “back to normal”? Who may be harmed in this process? What is the impact on people with disabilities in particular?
- How can we continue to use and expand upon the strategies and technologies utilized since Covid-19 to further accessibility and justice?

CLIMATE CHANGE

In the emerging climate crisis, individuals with environmental illnesses, autoimmune diseases, and other disabilities are often experiencing the effects of environmental changes first and/or most severely. The International Climate Justice Movement has widespread support and involvement from folks with disabilities who are already experiencing the effects of the climate crisis in a particularly harmful way.

BEYOND THE ADA

While the passage of the ADA in 1990 sparked a variety of much-needed changes, many Americans perceive this legislation as having “solved” inaccessibility, instead of seeing it as the invitation to continually imagine new possibilities that it should have been – and still can be! Basic ADA compliance is not an endpoint when it comes to crafting accessible, inclusive spaces, but rather a place to begin.

The World Institute of Disability, along with other disability justice organizations, encourages us to consider how we can progress beyond disability rights (basic civil rights for people with disabilities) to disability justice - an intersectional, coalition-based approach to holistic cultural change that benefits everyone by centering and uplifting the needs of people with disabilities.

Future offerings in this toolkit series will invite the UMass community into deeper conversations about inclusivity beyond ADA compliance, and encourage readers to consider how we can all play an important role in cultivating environments that honor and promote true disability justice.
Community Voices:
PAM MANDLER
(she/her)
Research Fellow

I have been dealing with an undiagnosed, invisible, systemic issue for decades that comes and goes, and is slowly getting worse. I finally needed to look into disability benefits a few years ago, but filling out paperwork and having to define my limits was difficult. I am still coming to terms with knowing my limitations due to fatigue and brain fog. My symptoms aren't going to magically disappear, so the best I can hope for is more good days and less disruptive bad days.

I have a lot of feelings about being disabled! In my head I hear all of the negative things, like when I compare myself to my pre-disabled days and feel like I'm falling short. I am working on being kinder to myself and remembering that my body is doing the best it can with what it was given. When I started working in the 90s, there was pride in working all the time and putting in extra hours, but now I understand that I do better when I'm able to take physical and mental breaks.

Being part of the disability community offers an opportunity to connect with others who may experience disability very differently, but still encounter some of the same issues, like having to adjust expectations of oneself or needing to sit out some experiences – while also recognizing that there is still so much that we ARE able to do.

QUESTIONS FOR INDEPENDENT REFLECTION

- Do you think about disability and accessibility often or infrequently? Why?
- Which elements of this toolkit feel illuminating, challenging, and/or affirming to you? Why do you think that is?
- Where did your knowledge about disability come from? What messages did you receive about disabled people from your family and culture of origin? How and why have your ideas and beliefs changed over time?
- What is your personal connection to disability? What role does disability play in your life, or the lives of those close to you?

RESOURCES FOR CONTINUED LEARNING:
Disability History & Culture

- Readings and Media on Disability & Accessibility from the UMass Amherst Libraries
- Sins Invalid: An Unshamed Claim to Beauty in the Face of Invisibility (education and performance)
- History of Disability Identity, Culture, and Community, UMass Speaker Series (event recording)
- Disability History Timeline from the National Consortium on Leadership and Disability
- Crip Camp: A Disability Revolution (documentary film)
- Disabled Activists to follow on Instagram (list)
- Disabled Creators to follow on YouTube (list)

RECOMMENDED READS

- Care Work: Dreaming Disability Justice by Leah Lakshmi Piepzna-Samarasinha
- The Minority Body: A Theory of Disability by Elizabeth Barnes
- The Future is Disabled: Prophecies, Love Notes and Mourning Songs by Leah Lakshmi Piepzna-Samarasinha
- Disabled Faculty & Staff: Intersecting Identities in Higher Education edited by Mary Lee Vance
- Disability Visibility: First-Person Stories from the Twenty-First Century edited by Alice Wong
Community Voices:
JOY JARME
(siya/she/her)
Executive Assistant

“What does disability mean to you? How and why do you identify as part of the disability community?” I wrestle with these questions almost daily and there have never been any clear or uncomplicated answers. When I was 28, a CT scan revealed a large growth wrapped around my aorta and I was given 3 - 6 months to live. Spoiler: over a decade later, I’m still here, loving life and thriving as a taiko drummer, hula practitioner, and new dog mom. In the years that followed, I’ve been diagnosed with two other forms of cancer, all of which were treated surgically. Because of this experience, I wonder about who gets to be considered a cancer survivor. I haven’t been through chemotherapy or radiation. My medical team recommended a disability parking placard due to my unpredictable energy level and responses to further treatment, testing, and changing medications. At first, I balked. Do I deserve a placard? After all, I am mobile, for the most part, and have no immediately obvious disability.

I’ve also struggled with Generalized Anxiety Disorder (GAD). Getting through the day sometimes requires more spoons than I have available, especially when I am without my Emotional Support Animal (ESA). Should that be enough to qualify me for accommodations? Or am I just an overly empathetic human who needs to “toughen up”? What gives me the right to step up as a member of the disabled community? Whose validation do I need to gain membership? Am I being lazy? Or am I trying too hard? Am I a failure or just too much of a perfectionist?

These questions seem to be as much a part of my disability journey as the physical and mental symptoms. Claiming an identity as a person with disabilities has not always been a clear-cut decision, but naming my challenges has allowed me to seek the support that has greatly benefitted my daily life.

I share my experience to encourage those who may be facing similar hurdles to consider seeking information, resources, and options. These years have taught me that admitting the need for help is not a sign of weakness or defeat, but the strength to embark on a new journey.

QUESTIONS FOR GROUP DISCUSSION

- Where have we encountered or benefited from disability advocacy and activism in the UMass community? What are some ways that we could actively support and/or participate in this work?
- What would it look like for us to move through our days with a lens of disability justice? What practices would we continue in our lives, relationships, and communities? What would we change?
- What actions would we like to take as a result of our independent and collective reflection? How will we hold ourselves and one another accountable for the goals we set?

RESOURCES FOR CONTINUED LEARNING:
Best Practices in Accessibility

- Inclusive by Design: A Disability Inclusion Toolkit from UMass President’s Office
- Online Meeting Best Practices from UMass Information Technology
- Accessibility and the Canvas Learning Management System
- Wheelchair Etiquette Training (video with audio descriptions)
- Service Dog Etiquette Training (video with audio description)

UMASS RESOURCES FOR STUDENTS
For disability community on campus:
- Karuth Silver Cultural Center
- Disability Culture Club
For accommodations and support:
- Disability Services
- Disability Housing Accommodations
- Assistive Technology Center

UMASS RESOURCES FOR STAFF & FACULTY
For disability community on campus:
- UMAIDA (UMass Allies for Illness and Disability Access)
- Alliance Against Ableism (contact alliance@umass.edu for information)
For accommodations and support:
- Accessible Workplace
- Assistive Technology Center

CREDITS
The Office of Equity & Inclusion is grateful to all our campus partners who contributed to the creation of this toolkit series.

Special thanks to Rachel Adams, April Bellafiore, Michele Cooke-Andresen, Samm Delorey, Kate Hudson, Griffin Leistinger, Melinda LeLacheur, Marcie Savoie, Ashley Woodman, Marcel Raisbeck, Linda Ziegenbein, and Fred Zinn.