Becoming Anti-Ableist: A Disability JusticeInformed Approach to Supporting the Disability Community



Maryland Center for Developmental Disabilities at Kennedy Krieger Institute

Building Partnerships. Changing Lives.

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Maryland Center for Developmental Disabilities at Kennedy Krieger Institute Community and Professional Development Training Program

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Overview and Guide Development

PROGRAM OVERVIEW: The Community and Professional Development Training Program at the Maryland Center for Developmental Disabilities (MCDD) at Kennedy Krieger Institute is committed to supporting and enhancing professional development opportunities for professionals and community members, and expanding their knowledge and skills to engage in effective advocacy, in order to improve the quality of life for people with disabilities and their families.

RESOURCE GUIDE DEVELOPMENT: This resource guide is designed to help individuals with disabilities, their families, care providers, and society at large as they strive to implement inclusive, anti-ableist practices across all system levels. The creation of this resource guide was supported by a targeted review of literature and resources that share the most relevant research on ableism and inclusive practices. Lessons learned are presented in this resource guide. Healthcare professionals and others using this guide should review and apply its recommendations according to their specific practice needs and goals.

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Introduction to Inclusive Practice

Ableism is a pervasive issue across society that inflicts harm on individuals with disabilities, ranging from stigma to health disparities (Engelman et al., 2019; Nario-Redmond et al., 2019). Ableism exists in a myriad of forms across all systems (individual, community, and society), which contributes to an underrepresentation of disability across education and training spaces (Engelman et al., 2019). As a result, there is significant research to support the need for inclusive, anti-ableist practices across system levels. When implemented across each level, these practices can reshape the ways disability is defined, perceived, and supported (Storey, 2007).

Inclusive practice means providing all members within a community equal access and rights to all components of the community (Bogenschutz et al., 2015). For example, this can take the shape of equal rights in programs and activities, removal of structural barriers, provision of accessible communication, opportunity for social friendships, and participation in policy decisions within the community. Members within the intellectual and developmental disability (IDD) community have defined inclusive practice as having the opportunity to establish friendships, a deep sense of connection, belonging, and acceptance within the communities they belong to (Carter, 2017).

Barriers to inclusive practice may be caused by discrimination towards people with IDD, policies or programs that do not support inclusion, or a lack of engagement and friendships within the IDD community (Bogenschutz et al., 2015). An anti-oppressive approach to inclusive practice allows a community to break down the barriers to inclusive practice and reduce stigma and discrimination towards people with IDD at all levels (Chanika & Logan, 2021).

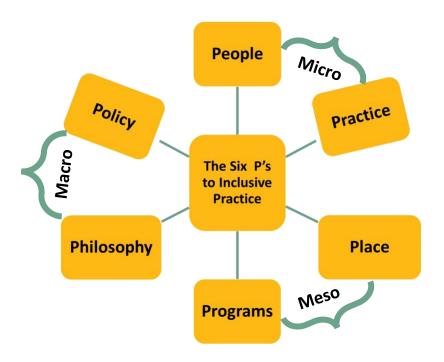


The Six P's to Inclusive Practice

The Six P's to Inclusive Practice is a promising pathway through which faith communities might be marked as a welcoming and inclusive space for people with disabilities and their families. This framework includes six areas that faith communities should consider in their advocacy efforts to support the full and meaningful participation of people with IDD and their families in their faith community life. The Six P's include Person, Practice, Place, Programs, Philosophy, and Policy (Ofonedu, 2022).

The Six P's to Inclusive Practice emphasize the interconnection between the micro (person/practice), meso (place/programs), and macro (policy/philosophy) level factors to fostering inclusive practice in faith communities. For the micro level, the focus areas to address include knowledge, attitudes, and behavior. Areas to address under the meso level include structural and event/activity components, whereas the focus areas to address under the macro level include organization values, and political and economic components.

The Six P's offer important insight into how faith communities can assess their strengths and assets in order to increase their responsiveness to the needs of people with IDD and their families. A survey incorporating the Six P's to Inclusive Practice is currently being developed and will be used as a part of the assessment tools on an MCDD faith-based initiative, led by the MCDD training director, that seeks to explore and strengthen inclusive faith support and sense of belonging in faith communities in Maryland.



Why is an Anti-Ableist Approach Important?

There is a common misconception that disability is a problem within society, but it is crucial that this mindset is deconstructed in order to remove the stigma attached to disability and create an inclusive society (Dunn, 2019). Ableism is so deeply embedded within society that it is normalized; however, in reality, this system of inequity and discrimination is the problem in itself that must be addressed (Andrews et al., 2021; Dunn, 2019). Implementing inclusive practice through an anti-ableist lens can help create this shift in mindset by highlighting that disability is a form of diversity as well as a marginalized identity (Andrews et al., 2021; Dunn, 2019).

With ableism deeply woven into the healthcare field, this system of oppression has detrimentally impacted the quality of care that is given to individuals with disabilities (Doebrich et al., 2020; Dunn, 2019; Engelman et al., 2019; Lund et al., 2020). Research shows that healthcare providers are uncomfortable working with individuals with disabilities and hold negative attitudes that influence the health outcomes of this community (Andrews et al., 2021; Doebrich et al., 2020; Dunn, 2019). For example, it is well-documented that clinicians assume individuals with disabilities experience a low quality of life, whereas self-reports from their patients indicate otherwise (Andrews et al., 2021; Doebrich et al., 2020;). Additionally, these implicit biases and attitudes have been shown to exacerbate access disparities to preventative care (Andrews et al., 2021; Engelman et al., 2019). As a result, it is important that providers are given the information and tools necessary to deliver equitable, culturally competent care to individuals with disabilities.

Ableism not only hinders the delivery of healthcare to individuals with disabilities, but it also creates barriers that prevent this community from accessing education, employment, and housing (Dunn, 2019; Nario-Redmond et al., 2019).

Forms of Ableism Defined

What is Ableism?

- Defined as the "prejudicial attitudes and discriminatory behaviors directed at disabled persons by nondisabled individuals" (Dunn, 2019, p. 666).
- This form of oppression can take many forms, which ultimately fall under one of two categories: covert or overt ableism.

What is Implicit Ableism?

- A subtle form of ableism that is perpetuated unintentionally or unconsciously (Dunn, 2019; Lund et al., 2020; Nario-Redmond et al., 2019).
- Individuals who perpetuate this type of ableism are often unaware of the stigma associated with their attitudes or actions. For example, implicit ableism may take the form of assuming that someone with a disability needs help or not speaking to someone with a disability directly (Dunn, 2019).

What is Explicit Ableism?

- A hostile form of ableism that is perpetuated with the intent of inflicting harm on individuals with disabilities (Dunn, 2019; Lund et al., 2020).
- Some clear examples of explicit ableism include hate crimes, mocking gestures, and avoidance (Nario-Redmond et al., 2019).

What is Internalized Ableism?

- A form of ableism that occurs within individuals with disabilities due to internalizing and accepting the oppression they experience (Dunn, 2019).
- Due to living in an ableist society, individuals with disabilities can adopt negative views of themselves and others in the disability community (Dunn, 2019; Nario-Redmond et al., 2019).

Definition of Key Terms

What is Disability Humility?

- Acceptance that individuals with disabilities are the experts on disabilityrelated issues, given that have unique expertise to draw off of from their lived experiences (Andrews et al., 2021; Doebrich et al., 2020; Reynolds, 2018).
- By embracing disability humility, non-disabled individuals can learn from and amplify the voices of individuals with disabilities (Andrews et al., 2021; Doebrich et al., 2020).

What is Intersectionality?

- A framework that considers the intersection of identities and the exacerbated oppression that follows for individuals of multiple marginalized identities (Doebrich et al., 2020; Dunn, 2019; Engelman et al., 2019; Fine, 2019; Lund et al., 2020).
- For example, a Black person with a disability will face oppression that is uniquely compounded by both racism and ableism (Engelman et al., 2019; Lund et al., 2020).

What is the Medical Model of Disability?

- A model that attaches stigma to disability by emphasizing the need for erasure and cures (Andrews et al., 2021; Dirth & Branscombe, 2019; Dunn, 2019; Engelman et al., 2019).
- The implications of this model include the historical institutionalization and silencing of individuals with disabilities (Engelman et al., 2019).

What is the Disability Justice Model?

- A framework that defines wellness holistically, prioritizes the voices of individuals with disabilities, and considers their intersectionality (Doebrich et al., 2020; Engelman et al., 2019).
- With this model, communities reshape the ways they measure quality of life and view disability overall, which help to mitigate health disparities among the disability community (Doebrich et al., 2020)

Consequences of Ableism

Personal Level

Stigma

• Implicit biases and stereotypes that portray individuals with disabilities as incompetent, or disability as inherently negative, perpetuate stigmatizing attitudes toward the disability community (Dunn, 2019; Friedman & Owen, 2017).

Historical Trauma

- Historically, the disability community has been harmed by eugenics (Doebrich et al., 2020; Lund et al., 2020).
- This violence continues to appear in healthcare when non-disabled bodies are favored over those with disabilities (Doebrich et al., 2020; Lund et al., 2020).

Objectification

 Viewing individuals with disabilities as 'inspirational' for simply existing in their body ultimately objectifies and stigmatizes disability (Andrews et al., 2021; Dunn, 2019; Nario-Redmond et al., 2019).

Internalized Ableism

 This internalized oppression can dictate whether individuals with disabilities form bonds with their community, utilize support aids, and address their needs, which may stem from a fear of not assimilating to the majority (Dunn, 2019).

Systemic Level

Economic Challenges

- Due to high healthcare costs and a lack of insurance coverage, indivduals with disabilities are often unable to access healthcare services (Andrews et al., 2021).
- The disability community also faces financial inequities as a result of high underand unemployment rates (Andrews et al., 2021; Dunn, 2019; Lund et al., 2020).

Health Disparities

- The disability community faces a lack of access to preventative care due to societal assumptions and stigma (Andrews et al., 2021; Engelman et al., 2019).
- Public health surveys also fail to account for the experiences of individuals with disabilities, which prevent solutions from being developed (Andrews et al., 2021).

Transportation

- Public transport is often physically inaccessible to individuals with disabilities, including unstable vehicles and unsafe lighting and infrastructure surrounding public transport (Engelman et al., 2019).
- These concerns make it increasingly difficult for individuals with disabilities to be present within the community (Andrews et al., 2021).

Education

- Individuals with disabilities often have few opportunities to receive inclusive education (Andrews et al., 2021; Dunn, 2019; Nario-Redmond et al., 2019).
- Students of color with disabilities alre also given disciplinary actions at an uneven rate in school settings, which feeds the schoolto-prison pipeline (Engelman et al., 2019).

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Barriers to Implementation: Person & Practice

Individual Level

Barriers

Lack of Knowledge and Education:

- Disability-related content is often overlooked in educational curriculums, particularly regarding the systemic factors that influence health disparities among the disability community (Doebrich et al., 2020; Engelman et al., 2019).
- Even when this content is addressed, it is often rooted within ableist ideologies rather than being framed through a disability justice lens (Andrews et al., 2021; Doebrich et al., 2020; Engelman et al., 2019). Therefore, providers' lack of knowledge and understanding about disability translates into poor quality of care for clients with disabilities (Andrews et al., 2021; Engelman et al., 2019).

• Implicit Biases and Negative Stereotypes:

- With a lack of knowledge and education on disability comes the perpetuation of negative assumptions and stereotypes about the disability community (Andrews et al., 2021;).
- As a result, these biases can invalidate the lived experiences of individuals with disabilities and further silence them from voicing their needs (Dunn, 2019).

Barriers to Implementation: Place & Programs

Community Level Barriers

Inaccessibility:

- Individuals with disabilities experience accessibility barriers both physically and programatically (Engelman et al., 2019).
- Physical accessibility barriers may include a lack of ramps or wide doorways for wheelchair users (Dunn, 2019). In contrast, programmatic accessibility barriers may appear in communities where there is a lack of collaborative partnerships with the disability community and a lack of staff who are trained to provide disability supports (Engelman et al., 2019).
- Inaccessibility prevents individuals with disabilities from being able to obtain needed services, tools, and support.

• Application of the Medical Model of Disability:

- Although it has been traditionally used in the healthcare system, the Medical Model of Disability perpetuates harm to the disability community by further stigmatizing disability as something that needs to be erased (Andrews et al., 2021; Dirth & Branscombe, 2019; Engelman et al., 2019).
- Subsequently, the stigma and implicit biases that are supported through this model inhibit individuals with disabilities from receiving quality care and support (Engleman et al., 2019)

Barriers to Implementation: Philosophy & Policy

Societal Level Barriers

Lack of Access to Healthcare Services:

- Across the literature, it has been well documented that individuals with disabilities face a lack of access to healthcare services, including preventative care (Andrews et al., 2021; Dunn, 2019; Engelman et al., 2019; Lund et al., 2020).
- This barrier is attributed to several factors, including lack of insurance coverage and low cultural competency in available services and tools (Andrews et al., 2021).
- A lack of access to care can put the disability community at a higher risk for adverse health outcomes and heighten health disparities due to restrictions in obtaining care (Engelman et al., 2019).

• Policies that Strip Disability Autonomy:

- Individuals with disabilities encounter policies that pose restrictions on their capacity to engage in decision-making, including policies surrounding guardianship (Nario-Redmond et al., 2019).
- As a result, these policies strip disability autonomy and reinforce false narratives that individuals with disabilities are incapable of decision-making (Nario-Redmond et al., 2019).

Strategies/Recommendations for Implementation

Incorporate Disability History and Culture into Curriculums and Training

- To better understand the disability community, it is crucial that disability history and culture are embedded into academic and professional training curriculums (Dunn, 2019; Nario-Redmond et al., 2019).
- In doing so, students and professionals will gain a more accurate representation of the disability community and their needs.

Participate in Disability-Related Trainings

- Past research highlights the need for disability trainings to produce culturally competent professionals, specifically in the healthcare field (Doebrich et al., 2020).
- While cultural competency is a start, professionals are encouraged to foster 'disability consciousness', which digs deeper into the systemic and structural inequities that are faced by the disability community (Doebrich et al., 2020). This can be fostered in the workplace by designing curriculums and training procedures with critical disability studies in mind (Doebrich et al., 2020).

Collaborate with the Disability Community

- Research has found that individuals who have more working experiences with individuals with disabilities also have broader definitions of disability that allow them to view the community holistically (Friedman & Owen, 2017).
- As a result, it is imperative that collaboration with individuals with disabilities is prioritized in order to de-stigmatize disability and facilitate disability-led initiatives.

Increase Disability Representation

• Individuals with disabilities, especially those who hold multiple marginalized identities, must be represented across positions of power and authority in various settings in order to facilitate the development of inclusive policies (Andrews et al., 2021; Doebrich et al., 2020; Lund et al., 2020).

Develop and Support Policies that Extend Beyond Inclusion

- While it is important to ensure policies uphold the inclusion of individuals with disabilities, scholars must strive to dismantle oppressive systems and reconstruct them through the development of transformative policies (Fine, 2019; Mladenov, 2016).
- It is important that the community is also made aware of supportive policies for individuals with disabilities. For example, supported decision-making serves as a helpful alternative to guardianship for individuals with disabilities to help them maintain their autonomy and promote self-determination.

Tips for Cultivating Disability Humility

Reflect on Implicit Biases and Stereotypes
Associated with Disability

- Consider your past understanding and familiarity, or lack thereof, with disability
 - What was your view of disability?
 - How did people in your life talk about disability?
 - What biased representations of individuals with disabilities did you see portrayed in mass media?
- Learn about ableism and how society has historically stigmatized disability

Redefine the Concept of Normalcy

- Deconstruct ableist definitions of normalcy (Doebrich et al., 2019; Dunn, 2019)
 - Extinguish the idea that disability is abnormal, as this stigma only further ostracizes and isolates individuals with disabilities (Andrews et al., 2021; Doebrich et al., 2019)
 - Instead, look at disability as another form of diversity that should be embraced and accepted in society (Doebrich et al., 2019; Dunn, 2019)

Acknowledge the Expertise of Individuals with Disabilities

- Leverage the voices of individuals with disabilities by creating and holding space for their valuable perpsectives (Doebrich et al., 2019; Lund et al., 2020; Reynolds, 2018).
- Recognize that your understanding of disability will never match the full scope of experience that individuals with disabilities know themselves (Andrews et al., 2021; Doebrich et al., 2019; Reynolds, 2018).

Assess Uneven Power Dynamics

- Recognize the inherent privilege that one has as a non-disabled person in society due to ableism (Dunn, 2019; Lund et al., 2020).
 - Use this position of privilege to elevate individuals with disabilities (Lund et al., 2020)
- Strive to be an ally to the disability community and an advocate for disability justice (Dunn, 2019).

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Tips for Implementing the Disability Justice Model

Amplify the Voices of the Disability Community

- Center the voices of clients with disabilities and acknowledge that they are the experts on their lived experiences (Andrews et al., 2021; Doebrich et al., 2019; Reynolds, 2018)
 - Create projects or research opportunities that are intentionally designed with individuals with disabilities at the forefront (Fine, 2019)
- Gather insights from disability scholars and activists (Doebrich et al., 2019)
- **Provide client-centered care** that gives power to individuals with disabilities (Doebrich et al., 2019)

Define Wellness from a Holistic Lens

- Normalize interdependence and highlight its value (Doebrich et al., 2019)
 - As disability activist Stacey Milbern Park described, everyone leans on one another for support and deeming certain supports as 'unacceptable' promotes ableism (Doebrich et al., 2019)
- Address intersectionality (Doebrich et al., 2020; Engelman et al., 2019; Fine, 2019; Lund et al., 2020)
 - Make an effort to learn about clients' identities and use their background to inform care plans and procedures (Engelman et al., 2019; Lund et al., 2020)
- **Promote disability pride** for those who embrace disability as an important aspect of their identity (Dunn, 2019; Nario-Remond et al., 2019)
 - Research has shown that disability pride exhibits buffering effects that can ease the negative outcomes associated with stigma (Lund et al., 2020)
- Reframe measurements of quality of life to be inclusive of the disability community (Andrews et al., 2021)
 - Deconstruct and erase false narratives that suggests that disability inherently predicts a low quality of life (Andrews et al., 2021; Reynolds, 2018)

Consider Disability Oppression

- Learn about historical trauma faced by the disability community
 - For example, the eugenics movement heavily contributed to the distrust individuals with disabilities feel toward the healthcare system (Doebrich et al., 2019)
- Use structures of oppression to inform practices (Doebrich et al., 2019)
 - Consider the social, political, economic, and legal inequities that harm individuals with disabilties and how they can be addressed

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Tips for Implementing Inclusive Practice

- ✓ Ensure practices not only address architectural, programmatic, and communication barriers, but also attitudinal barriers
- ✓ Incorporate activities that are oriented to abilities and strengths, respectful of differences, remain personcentered, and are accessible to all
- ✓ Foster community partnerships, collaborative efforts, empowerment, and self-advocacy for individuals with disabilities
- ✓ Articulate and foreground the fundamental principles of the organization or program
- Establish and maintain closer relationships with disability organizations
- ✓ Create safe shared spaces and opportunities to build connections with individuals with disabilities and their families
- ✓ Join efforts that promote social justice through community activities and teachings that embrace individuals with disabilities
- ✓ Support and host disability etiquette trainings for the community and practice power/voice sharing

(Griffin et al., 2012)

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Helpful Resources

- Americans with Disabilities Act: A Guide to Disability Rights Laws Reviews disability rights laws that ensure individuals with disabilities are protected.
- Autistic Self-Advocacy Network: Led by and designed for autistic individuals with the goal of amplifying the voices of this community to better inform policies and accessibility.
- Autistic Self-Advocacy Network: Planning Accessible and Inclusive Organizing Trainings Highlights barriers to participation that individuals with disabilities face in self-advocacy trainings and offers a disability perspective on creating inclusive trainings.
- Centers for Disease Control and Prevention: How to Protect Yourself & Others Offers guidance on how to protect the community from the spread of COVID-19.
- Collaborative on Faith and Disabilities Provides a tab with resources of webinar series, research projects, and other videos on topics relating to inclusion within faith communities.
- ❖ <u>Disability Alliance BC: Anti-Violence Resources</u> Offers documents to help individuals with disabilities as they navigate the criminal justice system.
- Disability and Faith Forum Provides an overview of what an inclusive ministry is, common barriers to inclusivity, and short video clips.
- Disability & Philanthropy Forum: Resource Library Offers resources on how to promote disability justice and mental health acceptance within philanthropy spaces.
- ❖ <u>Disability In: Resource Library</u> Shares trainings, fact sheets, accessibility tips, and additional disability justice resources to improve workplace inclusion for individuals with disabilities.
- Disability Visibility Project: Provides a platform for individuals with disabilities to share original pieces of work and create a community that speaks out against ableism.
- Discipleship Ministries: The CARES Act May Help Your Church Shares information on how the CARES Act may be helpful for churches.
- ❖ For Community and Faith Leaders: Creating Community Connections for Mental Health Offers advice to faith leaders on how to create an accepting environment for individuals struggling with mental health.
- Invisible Disability Project: Shares first-hand accounts from individuals with unseen disabilities about their experiences with ableism.

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- Jewish and Faith Inclusion Provides toolkits and other resources on faith-related topics and disability inclusion.
- Joni and Friends: Developing a Disability Ministry Provides guidance on how to create a disability ministry.
- Maryland Center for Developmental Disabilities: Disseminates information and research findings related to the disability community that can be helpful for families, care providers, and organizations.
- ❖ National Conference for Community and Justice: Ableism Shares a host of important information related to ableism, including a historical timeline, videos with first-hand accounts from individuals with disabilities, and reflection questions about ableism.
- ❖ National Conference for Community and Justice: Neurodiversity Highlights the importance of neurodiversity through various diagrams, videos, supplemental resources, and reflection questions.
- National Disability Rights Network: Accessibility Guidelines Offers guidance on how to create materials and host meetings that remain accessible to individuals with disabilities.
- Project LETS: Offers a host of supportive resources for concerns surrounding mental health, education, and legal rights for individuals with disabilities.
- Putting Faith to Work Offers a supportive model to faith communities on how to support individuals with disabilities searching for jobs.
- Rooted in Rights: #AccessThat Provides tutorials on tools that allies and advocates can use to make their digital media accessible to viewers with disabilities.
- Sibling Transformation Project: Anti-Ableism Training Unites siblings of individuals with disabilities in an effort to promote anti-ableism and offers trainings for other organizations to promote disability justice.
- ❖ <u>Spectrum Connections Therapy:</u> Outlines the components of a neurodiversity-affirming psychotherapy approach for therapists with clients in the autism community and other neurodivergent populations.
- Substance Abuse and Mental Health Services Administration: Faith-Based and Community Initiatives
 Offers guidance on how faith leaders and spaces can support mental health services.
- ❖ The Arc Maryland: Supports the rights of the disability community through training, programming, and advocacy.
- Therapist Neurodiversity Collective: Provides a host of infographics and supplemental resources that can assist providers, professionals, and community members in anti-ableism education.

- U.S. Department of Health and Human Services: Center for Faith-based and Neighborhood Partnerships Provides toolkits, documents, and webinars that may be helpful for faith spaces to become inclusive of those with mental health struggles.
- U.S. Department of Health and Human Services: Considering Faith, Community, and Mental Health During the COVID-19 Crisis Provides support to faith leaders in different religious spaces who are navigating mental health struggles in the midst of the COVID-19 pandemic.
- Vanderbilt Kennedy Center Provides tips and tools on how to help foster inclusion within faith communities.

Media Resources

- ❖ AAIDD Religion and Spirituality Interest Network Offers a recorded webinar with perspectives and advice from leaders of varying backgrounds of faith communities.
- Autistic Women and Non-Binary Network: Webinars Offers an archive of accessible webinars that shed light on intersectionality, disability justice, access to healthcare, and the effects of ableism in a variety of spaces.
- Disability Access and Inclusion Training Series for Jewish Organizations and Activists Offers multiple training webinars for disability inclusive topics.
- Disability Justice Project: Shares videos on disability-related topics, such as inclusion, mental health stigma, and barriers to healthcare.
- Included: The Disability Equity Podcast Lists various podcast episodes related to disability equity and justice, including topics of allyship, intersectionality, employment, voting, and advocacy.
- ❖ TEDxTalks: Confronting Ableism Shares a first-hand account of an individual's experience with an invisible disability and this person's perspective on the importance of dismantling ableism as a society.
- ❖ TEDxTalks: Purposeful Steps Away From Ableism Highlights the various ways that ableism impacts individuals with disabilities across society and the ways in which society can step away from ableist language.
- When Creating Inclusive Spaces, Talk to Disabled People Discusses the importance of collaborating with the disability community in order to promote inclusion and justice within community spaces.
- #ExpectAbilityTU: Lists a playlist of videos that amplify the voices of individuals on the autism spectrum within the Towson University community.



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